

Exploring Nursing Advocacy in Relation to Truth Telling in Cancer Care

A Literature Review

By

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### **Abstract**

Truth telling in cancer care is a complex and challenging issue for families and health professionals. Sometimes patients' needs for knowing the truth about diagnosis or prognosis are undermined by families' requests of non-disclosure and by the dominant ideologies held by the professionals working within the health care system. Such cases present unique challenges for nurses and raise questions about the advocacy role in nursing. In this paper, I have reviewed 52 nursing research and theoretical articles, book chapters, and nursing practice guidelines to explore the concept of nursing advocacy in truth telling to cancer patients about their diagnosis and prognosis. I have examined the relevance of nursing advocacy in truth telling, the context in which truth telling should occur, and explored the factors that would support or hinder advocacy in truth telling to cancer patients.

Advocacy in truth telling means providing patients with access to the information in relation to diagnosis and prognosis based on patients' needs and desires. The literature reviewed for this paper and the nursing standards of practice and Code of Ethics provide strong support for advocacy in truth telling as part of the nursing role and within the scope of practice. Nevertheless, collaboration between nurses and other health professionals would enhance nurses' abilities to advocate for patients' needs for information. These needs should be assessed on continuous bases and information should be provided based on patients' expressed needs and wishes. From an analysis of the literature reviewed both some supporting and hindering factors that would affect nurses' abilities or willingness with regards to advocacy actions are discussed. Following the analysis, I offer some recommendations for nursing education, research, and creation of

strategies in the areas of practice and policy making. As part of the recommendations for practice, I present a preliminary assessment tool that can be used for evaluating patients' needs for information and conditions that can affect provision of that information (Appendix A).

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## Exploring Nursing Advocacy in Relation to Truth Telling in Cancer Care

### A Literature Review

Patients frequently describe the moment they learn about cancer diagnosis as one of the most devastating experiences of their lives (personal communication). Such distressing news is understandably difficult for patients, families and health professionals. The challenges of truth telling to cancer patients are sometimes intensified when a conflict of ideologies and values exists between health professionals and families. Health professionals may adhere to the principle of patients' autonomy and informed consent which dictates providing patients with "full information" (BC Cancer Agency, 2004, p.1). Families on the other hand, may consider full disclosure shocking, disappointing and harmful to patients and may wish to withhold the truth (personal observation).

In my personal and professional experience, informing cancer patients about their diagnosis or prognosis has proved to be complex and challenging. A few years ago, a close family member of mine was diagnosed and died from cancer in my home country of Iran, never knowing he had cancer. The decision to withhold the information was made by a few family members and the oncologist. I was uncertain of what the best action was to protect this family member's best interest. Therefore, I did not challenge the decision of non disclosure.

As an oncology nurse working at BC Cancer Agency (BCCA), I have witnessed situations where families request that patients not be told about diagnosis or prognosis. Such requests can create problems for health professionals especially where informed consents were needed for treatment decision making. Some patients refused supportive and palliative treatments because they were not fully informed of their palliative

conditions. In one case, a woman with advanced stage cervical cancer refused all types of pain medications in spite of experiencing excruciating pain, because she was concerned about the long term side effects of pain medications (personal observation). The patient's family had requested that the truth about palliative condition not be disclosed to patient and therefore this patient did not seem to fully understand her grave condition and the treatment plans that would suit her physical needs.

In some cases, oncologists complied with families' requests for non-disclosure and did not directly inform patients of their diagnosis or prognosis. Other oncologists, however, were strictly committed to informed consent and refused to see patients without families' permission to fully inform patients about their conditions. Although these cases differed in context and form, they had one thing in common: the patients' point of view was not considered. I could understand and relate to the ideologies that influenced the attitudes and decisions of the health professionals and families in the matter of truth telling. In my own culture, protecting people from bad news is not only considered an act of kindness, but also a duty and responsibility. On the other hand, I work in an environment that is mostly influenced by dominant Western ideologies about patient autonomy and individual decision making. In my experience, these conflicting ideologies have not always considered patients' points of view in terms of truth telling. Furthermore, I have found myself confronting ethical dilemmas about how to approach truth telling to patients. According to CNA Code of Ethics (2008), "ethical dilemma or questions arise when there are equally compelling reason for and against two or more possible courses of action, and where choosing one course of action means that something else is relinquished or let go" (p. 6). When both families and health professionals present

compelling reasons for telling or not telling the truth to cancer patients, nurses are left with no clear understanding of how to support and advocate for patients' needs for knowing the truth.

### **Purpose Statement**

Vaartio et al. (2006) states that “before nursing practice can truly adopt advocacy as an inherent and natural part of nursing, a clearer understanding is needed of how it is defined and what activities are needed to accomplish advocacy” (p. 282). In order to advocate for patient's needs for truth, nurses need to be aware and clearly understand advocacy in relation to truth telling and what proper actions they can undertake to support patients.

### **Objectives**

The purpose of this project is to review and critically reflect on the ways that nursing advocacy in truth telling is represented in the literature. My goal is to understand the philosophical and theoretical aspects of the concept of advocacy in truth telling as well as its practical aspects that would guide recommendations for nursing practice. In order to accomplish this purpose I have followed three objectives:

- 1) Exploring the ways advocacy in truth telling is conceptualized and understood within the nursing literature.
- 2) Identifying some of the factors that can potentially support or hinder nursing advocacy in the area of truth telling.
- 3) Offering recommendations for nursing practice, education, and research.

**Significance**

The significance of this project is to:

- 1) Raise awareness and increase the understanding of nurses' and other health professionals' about truth telling in general and nurses' advocacy role for truth telling in particular.
- 2) Clarify the concept of advocacy in truth telling and how nurses can undertake advocacy actions.
- 3) Identify supporting factors to increase nurses' awareness of their strengths and resources that can be utilized when nurses take on advocacy actions.  
Understanding factors that hinder advocacy would help nurses and nurse leaders to identify gaps in the nursing practice, working environment, and the organization culture, and strategize ways to fill these gaps.
- 4) Provide recommendations to facilitate nursing advocacy in the area of truth telling in an oncology setting.

**Approach to Inquiry**

I chose a "traditional or narrative" literature review as described by Cronin et al. (2008) as an approach for undertaking this review. Cronin et al. (2008) explain that "this type of review critiques and summarizes a body of literature and draws conclusions about the topic in question. The body of literature is made up of the relevant studies and knowledge that address the subject area" (p. 38). The different stages of the narrative literature review include 1) selecting a review topic, 2) searching the literature, 3) analyzing and synthesizing the literature, and 4) writing the review (Cronin et al., 2008).

**Selecting the topic**

Cronin et al. (2008) advises the reviewers to refine their topic to specific elements of the subject in order to create a manageable task of the review. My original interest in this project was exploring truth telling to cancer patients. However, the initial literature search yielded thousands of articles and book chapters written about different aspects of truth telling. By reflecting on my own practice, including the needs of nurses in BCCA, and my own passion and interest, I chose advocacy in truth telling as a topic.

**Searching the literature**

According to Newell and Burnard (as cited in Cronin et al., 2008), important criteria for literature search included “comprehensiveness and relevance” (p. 39). The main criteria for selecting the literature for my review included relevance to nursing advocacy and truth telling (or providing patients with information about diagnosis or prognosis). I did not limit my search to any specific date because of the limited number of articles that included both concepts. I excluded articles that were not written in English, focused on whistle blowing, or advocacy and truth telling in pediatrics. Although whistle blowing is about advocacy and truth telling, it does not specifically relate to my subject of advocating for patients’ needs for knowing the truth about their diagnosis or prognosis. Articles on consumer advocacy that is focused on consumer’s right to information on drugs, services, and costs, were also excluded for the same reason.

I used database search and ancestry search methods to find the articles for the literature review. Ancestry searching resulted in finding articles related to advocacy, many of which have been used in this paper. Although most of those articles were not directly related to the concept of truth telling, they included themes that were related to

supporting patients' needs for information. The electronic databases used were the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Medical Literature On-Line (Medline). The University of Victoria library staff and University of Victoria Info-line department were excellent resource, providing advice for search strategies and access to full texts of the articles that were not available via web link.

In the process of searching the databases, I first used key words such as advocacy (OR advocate), truth telling (OR truth disclosure), and cancer (OR oncology). Using these key words together in the search resulted in finding only a few articles, and using them separately yielded too many articles that were not related to the subject of advocacy in truth telling. Although this search did not provide me with many relevant articles, it showed the lack of theoretical and empirical research on the concept of advocacy in truth telling for cancer patients, a gap that should be addressed in nursing research.

In the next step, I directed my focus on advocacy and truth telling only and excluded cancer related key words from my search based on an assumption that understanding the concept of advocacy in truth telling can be extended to an oncology setting. I used *advoca\** and *truth* as search key words to find the relevant articles in the nursing literature cited at CINAHL and Medline. Each data base search yielded more than 250 articles. Most of those articles did not meet my eligibility criteria and were excluded. These search methods resulted in finding 44 articles related to the concept of advocacy in truth telling. During the literature review, I added three articles on the subject of "trusting relationship between nurse and patient" in order to understand this concept that greatly influences nurses' abilities to advocate for patients.

In addition, nursing guidelines from the Canadian Nurses Association, International Council of Nurses, and the College of Registered Nurses of British Columbia were used to provide background on professional and ethical standards of practice. No reference to advocacy in truth telling was found in BC Cancer Agency (BCCA) nursing practice guidelines. However, therapeutic communication and supporting treatment decision making is briefly mentioned in the Professional Development pathway for new nurses at BCCA (BC Cancer Agency, n.d.).

### **Analyzing and synthesizing the literature**

Cohen (as cited in Cronin et al., 2008) suggests a method for an effective and focused analysis and synthesis of the literature referred to as the “preview, question, read, and summarize (PQRS)” (p. 40). Preview of the literature was mostly done during the literature search. In the question stage, Cronin et al. (2008) advises the reviewers to create a system (such as indexing) to organize the information gathered from the literature. This system would include the information about the article such as the title, the author, the purpose, methodology, findings, and outcomes, as well as the reviewers’ own thoughts and comments. Summary “may include key thoughts, comments, strengths and weakness of the publication”. (p. 40). I found the indexing system effective for organizing the main characteristics of articles such as the title, author, and the year of publication. However, for organizing the findings of the literature I did not find the indexing system very useful. Instead I created a document divided by main objectives of the project. As I read the literature I gathered the themes under their related titles. For example, one of my main objectives was to explore how advocacy in truth telling was understood and conceptualized with the nursing literature. Themes related to this

objective included the description of advocacy in truth telling, the role of the advocate, and the context that advocacy should occur. I included my own thoughts and comments under each finding. This approach to organization of the findings kept me focused on the objectives of my project and prevented distraction from the main issue that I needed to address. This approach also enhanced a smooth transition from gathering the findings to writing the review.

### **Writing the review**

I divided the paper into three chapters as Cronin et al. (2008) had suggested: the first chapter includes the purpose of the review, literature sources, and key search terms; the second chapter discusses the findings of the literature; and the final chapter includes a concise summary of the findings and offering recommendation for practice, education, and research. The recommendations are a reflection of the literature review and my own personal experience. The recommendations are focused on three areas of education, research, and creation of strategies in the areas of practice and policy making. At the end of the paper, I suggest a preliminary assessment tool to guide nurses evaluate patients' needs for truth and the conditions that would facilitate the action of advocacy in truth telling.

### **Advocacy and Truth Telling**

There is an agreement in the literature that advocacy in truth telling means supporting patients in receiving the information they need to make an informed decision (CNA, 2004, 2008; Croot, 1997; Curtin, 1979; Gadow, 1980, 1989, 1990; Hyland, 2002; Jezewski, 1993; Kohnke, 1982b; Tuckett, 2006; Webb, 1987; Winslow, 1984). This suggests an approach to advocacy in truth telling that is focused on patients' needs for information and self determination. As Nelson (1988) states, focusing on patients' self determination is an approach to advocacy that differs from the old view of advocacy as acting on behalf of someone in order to protect his or her best interest. However, patients may need support from health professionals or families in order to access the information they need and to practice self determination. Although patients are the ones who can make decisions for themselves, they may not be able to do so in an environment that does not provide them with opportunities to know the truth. In this chapter, I explore how advocacy in truth telling is defined in the literature, who can take responsibility of advocacy for truth telling, in what context advocacy for truth telling can occur, factors that would support nursing advocacy in truth telling, and the factors that can hinder nurses' abilities or willingness in advocacy.

#### **Defining advocacy in truth telling**

Advocacy has been mainly described as actively supporting the interests of others (*A Dictionary of Nursing*, 2008; Canadian Nurses Association's Code of Ethics, 2008; International Council of Nurses' Code of Ethics, 2006; *Merriam Webster Dictionary Online*, 2010). It has also been described as defending, supporting, or maintaining a right and good cause (Canadian Nurses Association's Code of Ethics, 2008; *Merriam Webster*

*Dictionary Online*, 2010; Tahan, 2005). Tahan (2005) suggests that advocacy also means drawing attention to and support for a good cause. In practice, these descriptions are not very clear and can be subjected to different interpretations. Families, health professionals, and patients may hold different views of what defines the best interest, support, rights and good cause.

According to *A Dictionary of Nursing* (2008) supporting the interests of patients' means "ensuring they are aware of their rights and have access to information to make informed decisions" (Entry advocate, para.1). In the light of this description, advocacy means supporting patients in exercising their rights to define their own best interests by providing them with the information that pertains to their decision-making. Gadow (1990) and Croot (1997) have used terms "truth" and "information" interchangeably in their articles. Similarly, in this paper, the terms truth and information are compatible and speak to those aspects of knowledge that are related to diagnosis or prognosis.

Furthermore, the act of advocacy in relation to truth telling is not equal to full disclosure or providing patients with information regardless of their wishes or needs. According to Trent (1985), truth telling is about ensuring patients receive information about what they feel they need to know. The College of Registered Nurses of British Columbia (2005) confirms this difference by advising nurses to "provide information in a timely and appropriate manner, taking into account the individual's abilities, age, culture, language, and preferences" (p. 2). In addition, the act of advocacy for truth telling involves respecting "values, customs, and spiritual beliefs of patients and their families" (International Council of Nurses' Code of Ethics, 2006, p.2).

In conclusion, advocacy for truth telling is a complex process that involves assessing patients' wishes, values, and beliefs, respecting their rights to self determination and providing them with the access to the information that they need to make informed decision.

### **The role of advocacy for truth telling**

Providing patients with information has been acknowledged as part of nurses' responsibilities (BC Cancer Agency, n.d.). In my experience at BCCA, nurses provide patients with detailed information when patients are aware of their diagnosis and treatment plans, request the information, and seem to understand the information easily. However, nurses are not provided with clear guidelines or expectations when truth telling becomes challenging as a result of conflicting values and ideologies. For example, I have observed that when families do not wish patients to be informed of the truth, nurses are often compliant with oncologists' decisions and approaches in telling or not telling the truth (personal observation). Although research is needed to clearly understand BCCA oncology nurses' attitudes and practices with regards to advocacy in truth telling, a few research studies of nurses' attitudes toward advocacy found that assessing patients' wishes and beliefs, providing information, and assisting patients in decision making was identified by nurses as acts of advocacy (Bu & Wu, 2008; Mallik, 1997b; Negarandeh et al., 2008).

Reflecting on my practice, I recall situations where some nurses, have shown (perhaps unknowingly) some acts of advocacy. For example, in some cases nurses (including myself) listen to patients' concerns, open a discussion about patients' understanding of their situations, help patients gain awareness of how their symptoms

relate to their disease progression, and encourage patients to discuss their concerns with physicians (personal experience and observation). However, during those actions, I have been cautious, uncertain of my role, and concerned about stepping out of my boundaries as a nurse.

Therefore, one of the questions that directed my literature review was to find out if it is nurses' role to actively advocate for patients who do not know the truth about their diagnosis or prognosis. In the literature reviewed, the authors collectively confirm that advocating for patients' wishes in relation to knowing the truth is within nurses' role and scope of practice (CNA, 2004, 2008; Croot, 1997; Curtin, 1979; Gadow, 1980, 1989, 1990; Greenlaw, 1980; Hyland, 2002; Jezewski, 1993; Kohnke, 1982b; Tuckett, 2006).

Nurse philosophers such as Curtin (1979) and Gadow (1989) go even further to suggest that nurses are placed in the best position to advocate for patients to ensure getting the information they need. They suggest that nurses spend the most amount of time with patients and provide them with intimate physical and emotional care. This can lead to a personal and comfortable relationship between nurses and patients in which patients feel safe to discuss their concerns and questions about their conditions. These statements may convey the idea that building a trusting relationship with patients is a process that requires time. Therefore, considering the time-constrain nurses may face in today's health care system, nurses' abilities to build a trusting relationship with patients, that is required for advocacy actions, may be questioned.

In fact, some authors challenge the view of nurses being in the best place for advocacy (Donavan, 1989; Hyland, 2002; Melia, 1987). The nurse-patient relationship, the concept of advocacy described by Gadow (1989) and Curtin (1979), has been

questioned by Hyland (2002) and Melia (1987). These authors suggest that nurses do not always have time to spend with patients to build up a trusting relationship adequate for advocacy. Furthermore, Hyland (2002) and Donovan (1989) further suggest that advocacy is not unique to nurses and can be done by any health professional.

Although I agree with Hyland (2002) and Melia (1987) that nurses' workload and the limited time they spend with patients can affect their ability to advocate, I do not consider the workload and limited time as valid reasons to wave nurses of responsibilities that are clearly identified in nursing professional and ethical standards of practice (CNA Code of Ethics, 2008). According to CNA Code of Ethics (2008), nurses are responsible to "provide persons in their care with the information they need to make informed decisions related to their health and well-being" (p. 11). I do not suggest that the amount of time nurses spend with patients is an insignificant factor in building a trusting relationship that is required for advocacy. Spending time with patients not only contributes to building trust and connection, but also provides more opportunities for assessing and supporting patients' needs for information (Schroeter, 2000). However, like any other nurses' responsibility towards their patients, I believe advocacy needs to be recognized, validated, and incorporated as part of nurses' time and workload.

Furthermore, the amount of time nurses spend with patients is only one of the ways of building a trusting relationship with patients (Lotzkar & Bottorff, 2001; Mok & Chiu, 2004; Morse, 1991). In a phenomenological study by Mok & Chiu (2004), patients and nurses identified themes in developing trusting and connected relationship that included "understanding the patients' needs, displaying caring actions and caring attitudes, providing holistic care, and acting as the patients' advocate" (p. 479). In an

observational study in an oncology unit, Lotzkar & Bottorff (2001) learned that, for building relationship, continuity of care was more important than the time nurse spent with patients. Morse (1991) suggests that although time is important in developing a relationship between patients and nurses, some circumstances such as the personality factors and the desires of the nurse and patients can affect (sometimes negatively) how the relationship develops.

The themes identified above, mirror my experience in developing a connection and trusting relationship with my patients. Additionally, in my experience, sharing the same culture and language may enhance the trusting relationship between nurses and patients. According to one of my Iranian patients, who was fluent in both English and Farsi languages, patients may be more comfortable discussing their concerns and questions with a nurse with whom they share culture and language (personal communication). In another case, an Iranian family member, who did not wish his wife (a cancer patient) know the truth about her poor prognosis, expressed a sense of trust and comfort discussing his concerns with me as I, as an Iranian, may have been able to better understand his reasons behind non-disclosure (personal communication).

I agree with Donovan (1989) and Hyland (2002) that advocacy can be done by any health professional. In fact I think leaving the responsibility of truth telling solely to nurses, considering the overwhelming responsibilities nurses face with their workload, can become problematic. I believe other health professionals, based on their role in patient care and their specific relationships with patients may be able to share the responsibility with nurses to advocate for truth telling.

However, health professionals such as oncologists may not always have opportunities to assess patients' desires for information and provide them with such information. For example, oncologists often see patients during the short visits to the clinics for consultations or follow up. These limited times with patients may only allow for physical assessment of disease progression or respond to treatments. As it was mentioned before, in this limited time, oncologists may either provide information regardless of patients' wishes for knowing the truth or comply with families' request for non disclosure. Furthermore, the literature on advocacy suggests that some patients may not understand or choose not to hear the information provided by their physician or may feel afraid to ask questions of physicians and may feel more comfortable to ask their questions from nurses (Greenlaw, 1980; Mallik, 1997b; Salladay, 1995).

Would the circumstances, mentioned above, indicate that nurses are best suited to advocate for truth telling as Gadow (1989) and Curtin (1979) had suggested? Perhaps that is the case in some situations. The important point, however, is being aware of the roles that different health professionals can play in supporting patients' needs for knowledge. It may not be about competing for advocacy role, but more about collaborating in order to protect patients' wishes (Curtin, 1979; Donovan, 1982). According to Donovan (1982), "a collaborative model offers open communication, mutual decision making and mutual respect for integrity of all parties involved that would protect patient's autonomy" (p.23). Furthermore, Donovan (1982) proposes that nurses are in best position to facilitate such collaboration. Collaboration is also an important part of nursing practice guidelines. According to CNA Code of Ethics (2008), "nurses collaborate with other health care providers and other interested parties to maximize health benefits to persons receiving

care and those with health-care needs, recognizing and respecting the knowledge, skills and perspectives of all” (p. 10).

The collaboration between nurses and other health professionals would utilize the strengths of each health professional in advocacy for truth telling and minimize the limitations of each role. One of the strengths of the nurses is their abilities to build a trusting relationship with patients. Nurses may have the opportunity to assess patients’ needs for knowledge. However, nurses may not be able to provide patients with all the information patients need. As part of their advocacy role, nurses can draw the attention to patients’ needs for knowing the truth and gain the support of their colleagues (Tahan, 2005). Nurses can communicate patients’ needs for information to appropriate health professionals such as oncologists or social workers who may be able to fill the gap in providing patients with needed and desired information. Communication with oncologists can be made if, for example, patients inquire about treatment options should their disease progress. A social worker would be of great support for patients who are exploring their end of life options (professional experience).

The role of the family in advocacy for truth telling has been debated in the literature (CNA, 2008; Curtin, 1979; Donovan, 1982; Lancaster, 1986; Trent, 1985). Donovan (1982) suggests that nurses should involve families in the collaboration. Considering family members in the collaboration may require assessment and evaluation of families’ issues and strengths. It can be argued that family members may know patients better than health professionals. Also in some cases patients are greatly influenced by their family members’ attitudes and decisions (personal observation). Some patients may even choose to leave the receiving information and making decisions to

their families (personal observation). According to Canadian Nurses Association Code of Ethics (2008) “a capable person may have different view on individualism and may defer to family for receiving information” (p.11).

On the other hand, family members may face issues in terms of truth telling to patients. Families may not be willing to disclose the truth in order to protect patients from harm and disappointment. Some family members may have difficulty understanding the information themselves because of factors such as language barrier, fear of health care systems and health professionals, and their social and educational backgrounds (personal observation).

Regardless of their intentions and capabilities, families often play an integral role in patients’ lives. Lancaster (1986) and Trent (1985) suggest families’ reasons for non-disclosure should be explored and their concerns and needs should be acknowledged and supported. Lancaster (1986) even suggests that, in some cases, we may be able to prepare families to see the benefits of truth telling and support the advocacy actions. Obtaining families’ support in advocacy for truth telling may be possible, but not without challenge. I do not recall even one case where we were able to persuade a family to support truth telling where the family had decided on non-disclosure. It is difficult to recount the reasons behind our lack of success in getting families’ support and agreement for truth telling. Perhaps instead of forcing the family members to accept what we see as benefits of truth telling, we need to evaluate our approach to gaining families’ support, create strategies on how to approach families who do not wish for disclosure of truth to cancer patients, and understand families’ beliefs in terms of truth telling (which may not be possible to change). Some patients may wish to know the truth in spite of their families’

disagreement for truth disclosure. According to CNA Code of Ethics (2008), “when family members disagree with the decisions made by a person with health care needs, nurses assist families in gaining an understanding of the person’s decision” (p. 11).

### **The context of truth telling**

Knowing how, how much and when to give information related to diagnosis or prognosis is as important as giving the information itself. Patients may not be ready to be given a large amount of information at once (Curtin, 1979; Gadow, 1990). Patients’ needs for knowing about their conditions should be assessed on continuous bases and information should be given based on patients’ expressed needs and wishes.

A valid and important question is how, how much and when to disclose the truth about diagnosis or prognosis? Croot (1997) suggests “always ask, never assume” (p. 11). Only patients can decide when and how much information they want if at all. As Gadow (1980, 1990) explains, the truth does not belong to health professionals, and thus they cannot decide if and when they should reveal the truth to patients. The truth belongs to patients and they need to form their own truth based on their values and interpretation of their reality (Gadow, 1990). According to Gadow (1990), “an example of the difference between statistical data and personal truth is the attempt by patients to ascertain not whether in objective terms they are dying, but whether they will be abandoned if they are dying” (p. 36). Similarly, my personal communications with patients and families have revealed that patients are often concerned about how (not when) they die. For example, experiencing pain, being isolated, being able to die at home, and being able to recognize loved ones, are among common concerns of patients’ and families’ (personal communication).

Most patients can identify what is important to them and what kind of information related to diagnosis or prognosis they need. In one research study, oncology nurses identified information and truth telling as a way of helping patients to making meaning of their experiences and “reconcile what was happening in health care with their understanding of their own experiences” (Steeves et al., 1994, p. 23). For these nurses providing patients with a small amount of information for an extended period of time was found to be more beneficial than forcing them with the full disclosure of information about their conditions.

Another important consideration is the fact that some patients may wish to leave the knowing and deciding to their family members. According to Canadian Nurses Association Code of Ethics (2008) “a capable person may have different view on individualism and may defer to family for receiving information” (p.11). By respecting patients’ wishes on non-disclosure, and assessing these wishes ongoing, we are in fact advocating for their right to autonomy and self determination (CNA Code of Ethics, 2008; Croot, 1997).

Equally important to what and how much of information about diagnosis or prognosis to offer to patients is how to offer that information. Croot (1997) suggests “the language you choose and the context you provide” is as important as the truth itself (p.10). Nurses need to show compassion and provide opportunities for patients to talk and ask questions. Opportunities can be provided by guiding a conversation, asking direct questions when it is appropriate, or simply listening. Patients’ pleas for information may be expressed non-verbally (Snowball, 1995). According to Webb (1987) “patients’ hints or pleads for reassurance, or their denial or withdrawal into depression, are equally

eloquent requests for information” (p. 35). In these cases, by simply asking patients what concerns them we open a door to an opportunity for truth telling. When we are aware of patients’ needs for information, we look and find opportunities to provide that information.

In spite of all the efforts to determine patients’ wishes for the truth, there are situations where the task is impossible. Gadow (1989) refers to patients who cannot express their wishes as “silent patients” (p.535). For example, patients who can not speak and understand English may have no way of communicating their wishes to nurses. It is not always possible to find interpreters to help with communication between nurses and non-English speaking patients. Families may be able to help nurses assess patients’ wishes about truth telling. However, families are not always present at the bedside, may not speak English themselves, or may not be willing to disclose the truth to patients. According to Gadow (1989) “silent patients create the greatest complexity for a position based on respect for patients’ self-determination” (p. 537).

Gadow (1989) presents two approaches that would potentially support silent patients’ wishes. One approach is a “beneficence position” by which nurses take an objective perspective to consider what would benefit silent patients (Gadow, 1989, p. 538). Another approach is “advocacy position” by which nurses take a subjective view to consider what would the individual patients “consider good” (Gadow, 1989, p. 538).

Although advocacy position presented by Gadow (1989) may be the best approach to supporting patients’ wishes in some cases, I am uncertain of its practicality in advocating for truth telling. For example, I may find chemotherapy treatment for an elderly patient with advanced disease cancer futile and may assume that the patient would

refuse chemotherapy if he or she knew the truth about treatment. However, I have seen many cases in which informed patients decided or even requested chemotherapy treatment in hope of living longer or have a better life quality. In spite of all of our efforts to be subjective and considerate of patients' experiences and wishes, we may find it difficult to avoid assuming and objectifying patients' wishes.

### **Supporting Factors**

Understanding the concept of advocacy in truth telling and its relation to the nursing role may be the first and possibly most important step in enacting the advocacy actions. However, advocacy for truth telling is a complex action that would require support and acknowledgement from all the health professionals within the health care system. Factors that support nurses' advocacy actions are within nurses' capabilities or potentials, and can be optimized by role recognition and the support of the health care system. The supporting factors that have been identified in this literature review include identifying advocacy as an ethical and moral responsibility, knowledge, communication skills, nurses' power, and leaders' support.

#### **Ethical and moral responsibility.**

Advocacy has been defined as a moral endeavor, one that supports a right and good cause (Bu & Jezewski, 2007; CNA Code of Ethics, 2008; Mallik, 1997b; Mallik, 1998; Merriam Webster Dictionary Online, 2010; O'Connor and Kelly, 2005; Pang, 1998; Redman, 2008). According to Bu and Jezewski (2007), "by successfully advocating for patients, nurses can increase their professional satisfaction, self-

confidence, and self-esteem, and maintain their personal integrity and moral principles” (p. 105).

Two studies on nurses’ attitudes and practices on advocacy especially in the area of truth telling revealed the feelings of moral distress and frustration in nurses that were provoked when they saw that patients’ rights were not considered and truth was withheld from patients (Mallik, 1997b; Pang, 1998). Similar to the experiences of these nurses, I have had some of the most challenging and morally distressing experiences in relation to truth telling to cancer patients. In fact, nurses in Mallik’s (1997b) study identified feelings of anger and frustration as one of the motivating factors for their advocating actions. Reflecting on my own experiences with moral distress, I think perhaps not the feelings of anger and frustration but what provokes those feelings may be considered a valid reason for advocacy for truth telling. Nurses may become frustrated when they have not been able to provide the necessary care for patients because of inability, lack of resources, or lack of education. These feelings may be exacerbated by the uncertainty and ambiguity of the advocacy role.

In another study, a few nursing elite in United Kingdom called advocacy a “good professional practice” and a “moral duty” for nurses (Mallik, 1998, p.1008). However, these nurse leaders expressed a sense of caution about professionalizing the advocacy role for nurses due to the concern about the lack of support from health care system and the risks that were involved with advocacy actions. From my understanding, this study conveyed that nurse leaders separated advocacy from professional responsibility. This study is quite limited and may not present the attitudes and believes of all nurse leaders. Furthermore, advocacy for informing patients has been supported and identified as a

moral duty and professional responsibility by nursing practice guidelines (Canadian Nurses Association's Code of Ethics, 2008; International Council of Nurses' Code of Ethics, 2006; College of Registered Nurses of British Columbia, 2005).

In my experience, not only the lack of role clarity but also the lack of clarity of what is considered the right action (should we or should we not tell) may be a source of moral distress. This literature review has provided me with an understanding that the choice of disclosure is only up to patients and my role is to provide patients with opportunities for knowing the truth and support them in their decisions. The concept and role clarity in advocacy for truth telling would not only support nursing practice, but it would also increase nurse leaders' awareness and understanding of the concept and their support for staff nurses' advocacy actions.

Knowing that advocating for patients' needs for truth about their diagnosis or prognosis is a moral and ethical responsibility, would motivate nurses to work through challenges of truth telling and provides them with job satisfaction and professional recognition (O' Connor & Kelly, 2005).

### **Knowledge.**

In the literature, knowledge is identified as a supporting factor for advocacy actions (Donavan, 1989; Doust, 1997; Kohnke, 1982a, 1982b; Mallik, 1997a, 1997b, 1997c; O'Connor and Kelly, 2005; Schroeter, 2000). The different areas of knowledge that have been identified in this literature review include: nursing knowledge and expertise (Kohnke, 1982b; Mallik, 1997b; O'Connor and Kelly, 2005), health care system and its specific culture (Kohnke, 1982b, Mallik, 1997c), nursing guidelines and codes of ethics (Kohnke, 1982b), advocacy strategies (Mallik, 1997b; O'Connor and

Kelly, 2005), and knowing self and others (Doust, 1997; Kohnke, 1982b; Schroeter, 2000). In this section I explain how the different areas of knowledge can facilitate nurses' abilities in advocating for patients' needs of knowing the truth about diagnosis or prognosis.

O'Connor & Kelly (2005) suggest that expert knowledge can facilitate patients' trust in nurses. According to these authors (2005), "while relating to patients on a human level was important, trust and confidence were instilled in patients through the ability of nurses to display expert knowledge of situation" (p. 460). I assume that the nursing knowledge and expertise suggested by these authors (2005) would include the knowledge of disease and treatments in a nursing practice. Mallik (1997b) suggests that "specialist knowledge" would promote "legitimacy position" of nurses in the health care system (p. 307). My experience shows that having high level of knowledge of cancer diseases and their treatment options support patients' confidence in nursing. Furthermore, as Kohnke (1982b) suggests, "When informing patients, we must either have the information or know where to get it." (p. 315). A knowledgeable nurse, who understands the medical aspects of patients' diagnosis and prognosis, can be more capable in assessing patients' needs for information about their diagnosis or prognosis, and better prepared to provide patients with such information.

Knowledge of the health care system in which nurses practice is important for advocacy actions (Kohnke, 1982b). This knowledge would support negotiating for patients' needs for information, and would lessen the risks of advocacy (Kohnke, 1982b).

The advocacy for truth telling about diagnosis and prognosis is within nursing professional and ethical standards of practice (Canadian Nurses Association's Code of

Ethics, 2008; International Council of Nurses' Code of Ethics, 2006; College of Registered Nurses of British Columbia, 2005). Knowledge of nursing guidelines for advocacy especially in the area of truth telling can help legitimize advocacy actions (Donavan, 1989).

Knowing how to advocate and negotiate patients' needs is part of the knowledge necessary for advocacy (O'Connor and Kelly, 2005; Mallik, 1997b). Foley et al (2002) suggest nurses' advocacy acts are often based on their instincts or what they have learned from other nurses. Work experience may provide nurses with valuable lessons in negotiating patients' needs for information and those lessons can be shared with other nurses. However, in some cases past experiences with truth telling may have not been very positive and may have taught nurses not to interfere to actively advocate for truth telling. Therefore, relying on experience and instincts may not always be a productive way of dealing with advocacy in truth telling. Creating strategies may be a more effective way in supporting both experienced and novice nurses in negotiating for patients' needs for truth.

Knowledge of self and others is an important supporting factor (Kohnke, 1982b; Schroeter, 2000). Realizing and acknowledging our own values and beliefs especially with regard to life, death, and disease can open our minds to understanding and supporting patients' values and goals (Doust, 1997; Kohnke, 1982b). In my experience, when nurses shift their way of thinking from "what I think is right for this patient" to "what would I want if I were in this patient's situation?" they take a step in understanding patients' points of view. For example, I personally expect to be told the truth should I become ill with a disease such as cancer. However, I would take caution when informing

one of my family members or Iranian friends of a cancer diagnosis because I know in my culture being straightforward in telling the truth shows lack of compassion and respect. Greatly influenced by this culture, I have often extended the same cautious approach to all patients, and even in some cases, refrained from truth telling. Considering how culture affects people's views on telling or learning about cancer diagnosis and prognosis, shows that truth telling is complex for both patients and nurses who care for them.

### **Communication skills.**

Good communication skills may be the most important factor in advocacy and truth telling. According to the literature, good communication skills enhance nurses' abilities in assessing patients' needs for information, creating a rapport with families and health professionals, negotiating with other health professionals for truth telling to patients, and reducing the risks of conflict (Bu & Jezewski, 2007; Donovan, 1989; Mallik, 1997a; O'Conner & Kelly, 2005; Tahan, 2005).

Such skills would support nurses to connect with patients and encourage them to discuss their concerns and questions (Donovan, 1989; Jezewski, 1993; Mallik, 1997b; Snowball, 1995). It is also important to communicate with families and assess their understanding of patients' situations and wishes (Jezewski, 1993). Having good communication and working relationships with other health professionals is necessary for nurses in order to gain their support and cooperation in advocating for patients' needs for the truth (Jezewski, 1993; Hyland, 2002; Mallik, 1997b; O'Connor and Kelly, 2005).

My experience has shown that although communication methods may vary based on people's specific needs and expectations, considering the main principles of active listening, mutual respect and understanding, and clear and honest expression of

information would go a long way in connecting with patients, families, and health professionals and bridging the gap of communication between them.

Equally important to having good communication skills is being aware of ramifications of insufficient and inappropriate communication actions. I have witnessed situations where health professional and families' persistence on their own points of view about telling (or not telling) the truth to patients intensified the conflict and resulted in anger and lack of agreement on supporting patients' best interests. Mutual respect, listening, and collaboration could have been much more productive in supporting patients' well being. Also families' understanding of patients' situations should be evaluated. Some families may not (or refuse to) comprehend patients' poor prognosis. Obviously these families would not support providing patients with information that they see as untrue. By recognizing families' feelings and providing them with information, we can support families and potentially gain their cooperation in truth telling to patients (Lancaster, 1986; Trent, 1985).

### **Nurses' power.**

Nurses' knowledge and skills, as well as their unique positions in providing care for patients can provide them with a power that can be well utilized in advocating for patients (Melia, 1994). In my experience, other health professionals have great respect for nurses and value their attitudes and views. Nurses can use their position in health care system to negotiate for patients' needs for truth telling. If patients are assessed and known to not want the truth, nurses need to support patients' decision and collaborate with other health professionals to support patients' wishes.

Nurses can use the time they spend with patients providing physical and emotional care to create opportunities for assessing patients' needs for information and give patients the information that patients want and request (Curtin, 1979). Sometimes nurses are able to give the information to patients and sometimes they need to communicate patients' needs for information to other health professionals such as physicians (Greenlaw, 1980; Winslow, 1984). This supports the idea of collaboration in advocacy when nurses seek support from other health professionals to provide patients with the truth. Nurses in Snowball's (1995) study suggested that even if nurses are not successful in their act of advocacy, the attempt would nonetheless show nurses' support for patients and it would make their relationship stronger.

#### **Leadership support.**

Nurses need the support of their leaders and administrators to safely advocate for their patients' needs for information (Bu & Jezewski, 2007; Donavan, 1989). Advocacy for truth telling is an "emotional and dangerous role" (Drought, 2007, p.128) that cannot be expected from nurses without providing strategies, skills, and support from leaders. According to CRNBC (2010), nurse administrators are responsible to provide a supportive environment for nurses to "promote and respect informed decision-making" and "preserve dignity" of patients they provide care for (p. 13).

At BCCA nursing leadership is divided into two main categories: practice leadership and clinical leadership. Practice leadership can support advocacy in truth telling by initiating and guiding empirical and theoretical research to create more knowledge and understanding of advocacy in truth telling. The knowledge that is created can be incorporated into guidelines and educational opportunities for nurses. Clinical

leadership can support advocacy for truth telling by recognizing and supporting acts of advocacy and creating a supportive environment with sensible workload management and resources.

### **Hindering Factors**

Enacting advocacy in truth telling may pose many challenges when nurses face barriers that prevent or stop their advocacy actions. Identifying and understanding these barriers may support creating strategies that would facilitate and encourage advocacy actions for truth telling. Hindering factors identified in this literature review include lack of role clarity, limited nursing education, inadequate knowledge and skills, some perceptions held by nurses, potential risks, and insufficient support system.

#### **Lack of role clarity.**

Ambiguity of the nursing advocacy role has been widely mentioned as one of the hindering factors for advocating for truth telling (Albarran, 1992; Altun & Ersoy, 2003; Bu & Jezewski, 2007; Bu & Wu, 2008; Donovan, 1989; Gadow, 1990; Negarandeh et al, 2008; O'Connor & Kelly, 2005; Vaartio et al, 2006). As Gadow (1990) suggests, in spite of all the policies on informed consent, patient education, and codes of ethics, the issue of truth telling is "far from being solved" for nurses (p. 33). When truth telling becomes very challenging, nurses tend to leave the matter of truth telling to physicians or to other health professionals to resolve (personal observation). Since nurses are not aware that advocating for truth telling is part of their role, they may not confront the challenge of truth telling to patients. On the other hand, I recall cases where nurses have shown act of

advocacy for truth telling but it has not appeared to be recognized, validated, and identified as such.

**Limited education, knowledge and skills.**

As mentioned earlier, nursing practice guidelines and standards of practice supports nursing advocacy actions. However, according to the authors in the literature, there is no clear guidelines or education for nurses on how to advocate for truth telling (Bu & Jezewski, 2007; Drought, 2007). Mallik (1997b) suggests that although philosophical definitions of advocacy have been presented in the literature, there is not a clear guideline how to enact advocacy. Therefore, even if nurses are willing to take on the role of advocating for truth telling, they are uncertain on what course of action they need to take. Foley et al (2002) suggest nurses' advocacy acts are often based on their instincts or what they have learned from other nurses. As it was explained earlier, relying on experience and instincts may not always be a productive way of dealing with advocacy in truth telling. Education, guidelines, and strategies are possibly more effective facilitators for advocacy in truth telling.

The importance of knowledge and communication skills in advocating for truth telling has been discussed previously in this paper. Although I recognize that limited knowledge and skills act as a hindering factor for advocacy in truth telling, I believe that the perception of limited knowledge and skills can be a more effective hindering factor. Some may find the process of gaining knowledge and improving the communication skills an undertaking that would take time and experience. Although this may be true, it could convey a message that advocacy for truth telling is an action that may not be suitable for new hires. Also, appraising knowledge and skills may be subjected to

personal judgment and sense of confidence. A nurse who is not confident in her or his knowledge and skills may refrain from advocacy for truth telling.

I do not suggest that nurses should embark on a complex action such as advocacy for truth telling regardless of their level of knowledge and skills. Previously, I have discussed the importance of knowledge and communication skills in facilitating nursing advocacy actions. Rather, I suggest that advocacy in truth telling should be given the same level of organizational recognition, support, and education as any other nurses' responsibility at BCCA. As I have already explained, knowledge has many aspects. Some aspects such as the one related to oncology, are considered necessary to oncology nursing and included in nursing education at BCCA. Other aspects of knowledge such as evaluating the attitudes and values of self and others can be developed during the process of advocating for truth telling. Communication with patients, families, and colleagues, can create knowledge that pertains to specific situations.

As I have explained through out this paper, advocacy for patient' needs for knowing the truth is part of nursing professional responsibilities, and needs nursing, leadership, and organizational recognition and support. Therefore, instead of considering the lack of knowledge as a hindering factor for advocacy for truth telling, I suggest we consider advocacy for truth telling as a responsibility for which we should seek the necessary knowledge and understanding.

### **Perceptions held by nurses**

Some of the hindering factors for advocacy in truth telling my include perceptions that nurses may hold in regards to advocating for patients' needs for knowing the truth.

These factors may include: perceived lack of authority and autonomy, and perceived lack of interest in advocacy in nurses.

Many authors have identified lack of authority and autonomy as a hindering factor for nursing advocacy (Albarran, 1992; Donovan, 1989; Gillan, 1994; Mallik, 1997a; Melia, 1994; Schroeter, 2007; Webb, 1987). It appears that the perceived sense of lack of authority and autonomy is partly self induced and partly influenced by the health care system. Limited knowledge and skills, for example, diminishes nurses' confidence in advocating for truth telling autonomously (Gillan, 1994). On the other hand, the lack of nurses' confidence in their knowledge and skills would negatively affect other health professional's willingness to trust nurses in their judgment and concerns about truth telling (Gillan, 1994). This further affects nurses' self respect and perceived sense of autonomy.

Dominant ideologies and culture can influence nurses' autonomy and authority. In a culture that favors physicians' authority, nurses may not have enough power to challenge physicians' decisions on truth telling if it disregards patients' wishes (Webb, 1987). Albarran (1992) suggests that, in spite of nurses' ethical concern, there is a general lack of confidence in nurses in their ability to advocate for patients. This statement maybe challenged by some nurses. Lack of confidence is a personal experience that may not be easily acknowledged by nurses. Some nurses may be quite confident in certain areas of nursing care, particularly the ones that are well established as nursing responsibilities, and not enough confidence in other areas where the role is unclear.

Furthermore, some authors suggest that patients may not fully trust or expect nurses to advocate for them (Albarran, 1992; Donovan, 1989; Melia, 1994; Nelson,

1988). According to the literature this lack of trust is in some cases related to the view that nurses are partners with medical staff (Albarran, 1992), and in some cases related to the fact that patients may not perceive nurses in a power position to advocate for them (Donavan, 1989; Melia, 1994; Nelson, 1988).

In my experience, the way patients view nurses and their abilities to advocate for truth telling may depend on different factors. One of the important factors could be the way nurses present themselves. For many patients, cancer diagnosis is their first experience with the health care system. Patients may have some general ideas of nurses' role and capabilities but it is how oncology nurses advocate for truth telling that shapes patients' beliefs in nurses' ability to advocate for them.

Melia (1994) suggests some nurses may not wish to advocate for truth telling for personal reasons. Nurses may be content and/or agreeable with the dominant ideologies and practices in relation to truth telling and do not see any reason to challenge them. This statement mirrors my observations in terms of truth telling, where in most cases, nurses are agreeable or compliant with physicians' decision in terms of truth telling. However, it is difficult to conclude that nurses' compliance with physicians' views is a result of their lack of interest in advocacy or nurses' agreement with physicians. Other factors that I have discussed in this paper such as lack of knowledge, role clarity, or confidence, may influence how nurses view and act advocacy for truth telling.

Melia (1994) also suggests that some nurses may see themselves in a better position to decide what is best for patients and may not wish to transfer that deciding power to patients. Similarly Kohnke (1982b) states "the advocate must want the client to have the information (we don't always want people to know too much)" (p. 315). I admit

it is difficult to overcome the ideology that we, as health professionals, know what is best for patients more than they do. In fact if we do not overcome this ideology, even when we are supposedly advocating for patients' needs for truth, we may, sometimes unconsciously, select the amount of type of information in order to manipulate patients' decision making towards what we think is right (Kohnke, 1982a).

### **Risks.**

Another barrier to advocacy for truth telling is the potential risks associated with advocacy (Bu & Jezewski, 2007; Curtin, 1979; Donovan, 1989; Drought, 2007; Hyland, 2002; Kohnke, 1982b; Melia; 1994; Nelson, 1988; O'Connor and Kelly, 2005; Snowball, 1995). One of the risks is the conflict between different opinions, interests, or ideologies (Donovan, 1989; Melia, 1994; Nelson, 1988; O'Connor and Kelly, 2005; Snowball, 1995). Families who do not want their patients to be informed about their diagnosis or prognosis may expect nurses to be on their side. Physicians may expect nurses to be team players and comply with their rules and advice. Colleague nurses may have differing opinion about truth telling and therefore may not support the advocating nurse. As Melia (1994) suggests, nurses may not wish to oppose the decisions of physicians as they may see physicians or themselves in better position to act on behalf of patients or decide for patients. Nurses may be reluctant to provide patients with truth because well informed patients may be perceived as more assertive, demanding, and difficult to manage (Brown, 1986). Informed patients may have higher expectations that could challenge and exhaust nurses (personal observation and experience). Nurses may not see themselves as able or willing to face such challenges especially when they are already overwhelmed with their workload.

Advocacy is a complex process that takes time and effort, and may be difficult for all the nurses to embark. Nelson (1988) suggests that sometimes, “patients who have had a nurse advocate may ask too many questions, want to do things their own way, and even be noncompliant” (p.140). Therefore, other nurses “may view client advocacy by the nurse as a problem” (Nelson, 1988, p. 140). Similarly Bu & Jezewski (2007) suggests that advocacy nurses are at risk of being “labeled as trouble-makers or bad co-workers by nursing colleagues” (p. 106). My limited experience with advocacy for truth telling cannot support or challenge the above statements. I would assume that in a real practice situation, advocating for knowing the truth about diagnosis or prognosis may raise some questions or discussions. However, I have never encountered a situation where the nurse, who acted based on ethical and professional standards of practice, been called a “trouble maker”. As discussed earlier, education and support for nurses can facilitate their adjustment to the concept and enacting of advocacy for truth telling.

Another potential risk for advocacy is legal action against the advocate (Bu & Jezewski, 2007; Curtin, 1979; Hyland, 2002). Bu & Jezewski (2007) and Curtin (1979) mention loss of employment or even licensure as the possible results of legal actions against advocate. It is difficult to imagine that in our health care system, where advocacy actions are supported by ethical guidelines and standards of nursing practice, the advocates can face legal actions that would lead to the loss of employment or licensure. However, the possibility of some legal actions against nurses or other health care providers cannot be ignored when it comes to informing patients about diagnosis or prognosis. I recall a situation where patient’s family threatened to sue the hospital if any

information about prognosis was disclosed to their patient. Understandably nurses would be very reluctant to advocate for truth telling to patients in these situations.

**Insufficient support system.**

Insufficient support systems have been mentioned in the literature as one of the hindering factors for advocacy (Donavan, 1989; Mallik, 1997b; Mallik, 1998). The support can be from nurses' colleagues, nurse leaders, and the healthcare system in which they practice. As it was mentioned earlier, colleague nurses and nurse leaders may not be able or willing to support the advocating nurse for truth telling. In one study, the nurse leaders cautioned against professionalizing advocacy due to various risks involved with advocacy actions (Mallik, 1998). These participants believed that advocacy was over-emphasized in the literature and too difficult to achieve (Mallik, 1998). Advocating nurses may not easily receive support from leaders with such attitudes. Interestingly, these nurse leaders counted the lack of support from nurse colleagues as a risk factor to advocacy (Mallik, 1998). They did not mention their own attitudes and beliefs in advocacy as a hindering factor, or the lack of support from the healthcare system and its culture.

The results of Mallik's (1998) study, triggers questions about the attitudes and concerns of nurse leaders in a Canadian health care system, specifically the leaders in an oncology setting such as BCCA. The nurse leaders at BCCA are possibly aware that supporting patients' needs for knowing the truth about diagnosis or prognosis is part of nursing practice guidelines and code of ethics. However, putting the concept of advocacy for truth telling into practice may be as challenging for nurse leaders as it is for staff nurses. According to Tracy Truant, one of BC Cancer Agency's professional nursing

practice leaders, there may never be a nursing guideline at BC Cancer Agency about truth telling (personal communication, June 8, 2010). Tracy stated that truth telling “is really about infusing concepts of ethical decision making, informed patient choice, patient autonomy, patient centered care, and the right to know” (personal communication, June 8, 2010). Similar to front line nurses, nurse leaders and other members of the health care team may need education and support to understand the concept of advocacy for truth telling and the strategies that can facilitate transition of the concept to practice.

## Discussion

### Summary of the literature

In the nursing literature, advocacy in truth telling is conceptualized as supporting patients' needs for information and self determination. Knowing the truth for some patients is possibly the most difficult yet the most important aspect of their cancer journey from which patients can make important decisions about their treatments and management of their diseases. This aspect of nursing practice has been strongly supported and identified as a moral duty and professional responsibility by nursing practice guidelines (Canadian Nurses Association's Code of Ethics, 2008; International Council of Nurses' Code of Ethics, 2006; College of Registered Nurses of British Columbia, 2005). In spite of strong support for advocacy in truth telling, the literature seems to be mostly focused on the theoretical and conceptual aspects of the advocacy and less on the practical aspects. In order to incorporate the concept of advocacy in truth telling into nursing practice, more research, education, and creation of strategies is needed.

There is an agreement in the literature that enacting advocacy in truth telling in a way that supports patients' self determination is not without challenges. The literature reviewed provides some insight into some obstacles that would hinder nurses' ability to advocate for truth telling. The most important obstacle may be that the role is not clarified, recognized, nor validated for nurses. The lack of clarity and recognition results in lack of support from colleague nurses, other health professionals, and nurse leaders. There are risks associated with advocacy in truth telling that can deter nurses from enacting advocacy in truth telling. Conflict of opinions, interests, or ideologies can

prevent nurses from advocating for their patients' needs for truth. Some nurses may be influenced by the dominant ideologies and would not wish to challenge them. Advocacy for truth telling may be viewed as complex, risky, and exhausting, and therefore nurses may not be willing or able to embark such action.

In spite of all the challenges, advocacy in truth telling is not impossible. Factors that would support nurses in this endeavor are within nurse's capabilities. Nurses can take advantage of their knowledge, relationship with patients, and communication skills to assess patients' needs for truth and support them in meetings those needs. Nurses are in a good place to relay patients' needs to other health professionals, gain their support, and start collaboration towards advocacy for truth telling. However, like any other nursing responsibilities, advocacy for truth telling needs the education and support of other health professionals and leaders. Sharing the responsibility of advocacy may improve our strengths and supports creating strategies for dealing with the hinder factors.

This review of the literature can provide nurses with an understanding of the concept of advocacy for truth telling. Advocacy in truth telling is different from just providing patients with information. It is more about providing opportunities for patients to gain realization of their realities. Regardless of age, culture, language, and education, all patients have rights to know about their diseases and their treatment and management options. Advocacy is supporting this right. Advocacy is a complex process that involves assessing patients' wishes, values, and beliefs, respecting their rights to self determination, and providing them with the access to the information they need to make informed decisions.

Admittedly, there is more emphasis in literature on the theoretical and philosophical aspects of advocacy in truth telling rather than on its practical aspects. A few researches on nurses' attitudes on advocacy have revealed that their occasional advocacy actions were based on their instinct of supporting a good cause or what they have learned from colleagues. The need for role clarity and sufficient guidelines on advocacy for truth telling is apparent.

This literature review could inform the creation of strategies for enacting advocacy in truth telling. Culture brokering and assessing patients' needs for truth are among those strategies that will be discussed later in this chapter. However there are some gaps in the literature on some important concepts. For example little is known about patients' understandings and expectations in relation to advocacy in truth telling which can be crucial in creating strategies and approaches.

### **Recommendations for Practice**

In this section, I have drawn from a review of the literature and reflection on my own experience to offer recommendations for practice in education, policy and practice strategy creation, and research. These recommendations introduce themes that can be incorporated into guidelines, education opportunities, and research projects for nursing at BC Cancer Agency. The importance of assessing patients' needs for information has been frequently mentioned in this literature review. I have taken ideas from this review of the literature to create a preliminary assessment tool that can be developed by BCCA nursing leadership as a tool to assess patients' needs for knowing the truth (Appendix A).

**Education.**

According to Mallik (1997a) “education should raise consciousness about patient advocacy” (p.135). In my experience, the lack of awareness of advocacy for truth telling may be the most important hindering factor for enacting nursing advocacy. As the literature suggests, nurses need education to understand what advocating for truth telling means and how it fits within their roles and scopes of practice (Altun & Ersoy, 2003; Bu & Jezewski, 2007; Donovan, 1989; Mallik, 1997a; Negarandeh et al, 2008; Nelson, 1988; Vaartio et al, 2006). I believe this education should not only address staff nurses, but also nurse leaders and other health professionals to promote an understanding of nurses’ role in advocacy for truth telling that would lead to collaboration and support from leaders and other health professionals.

Although not directly discussed in the current literature, education themes related to supporting and hindering factors, already discussed in this paper, can be considered for facilitating education about advocacy in truth telling in BCCA. Education regarding strategies to help nurses enhance their knowledge of oncology, knowledge of themselves and their patients, enhance their communication skills (Foley et al., 2002; Mallik, 1997a), and negotiate patients’ needs for truth with other health professionals. Learning how to handle hindering factors such as conflict (Mallik, 1997a), lack of support from nurse leaders and colleagues, and evaluating their personal concerns and ideologies in relation to truth telling to cancer patients would greatly enhance the nurses’ abilities in advocacy for truth telling. Some of these strategies will be discussed later in this chapter. Others need further theoretical and empirical research for structure and understanding.

Education at BCCA is usually done by means of new staff orientation, seminars, workshops, newsletters, emails, rounds, conferences, and preceptorship/mentorship programs. The education on advocacy for truth telling can be incorporated into these education opportunities for nurses at BCCA.

### **Strategies.**

As Jezewski (1993) suggests, “if advocacy is an essential characteristic of nursing and part of its philosophical basis, then nurses need broad-based models to implement advocacy in this practice” (p. 80). In this section I offer some strategies that can be developed further into a series of guidelines and action plans at BCCA. These strategies include referring to nursing guidelines and creating new guidelines, culture brokering, assessing patients’ needs for information, risk management, and collaborative advocacy.

### **Guidelines.**

Donavan (1989) suggests advocacy guidelines would not only safeguard nurses’ advocacy practices but also helps nurses to deal with hindering factors. As it has been mentioned in this paper, advocacy for providing patients for desired information related to diagnosis and prognosis is supported by nursing practice guidelines. The therapeutic communication and supporting treatment decision making has been briefly mentioned in the Professional Development Pathway for new nurses at BCCA (BC Cancer Agency, n.d.). In this pathway, two themes can be identified in relation to advocacy for truth telling including “practical strategies for communicating with patients with cancer and their families” and “strategies for supporting treatment decision-making” (BC Cancer Agency, n.d., p. 9). These guidelines, although not clear in strategies for enacting

advocacy, are foundations, upon which more clear guidelines for nursing practice can be built.

***Culture brokering.***

According to Jezewski (1993), anthropology authors describe many functions for the culture broker including “bridging gaps in cultural meaning or gaps in understanding between health professional, the patient, his community and the broader social system” (p. 80). The culture broker also mediates “between the lay, popular, and professional traditions of health care delivery” (Jezewski, 1993, p. 80). In this model, culture is not entirely referred to ethnicity, although it may encompass that definition. The culture is referred to the specific “set of values, beliefs, behaviors, and language” of health care system that, in most cases, is experienced as a foreign domain for patients (Jezewski, 1993, p. 80). In the area of truth telling, culture brokering can help patients to become familiar with the health care system and feel safer not only with nurses but also other health professionals to express their concerns and ask questions.

LaFargue (as cited in Jezewski, 1993) describes the culture broker as someone who “can interpret expectations between groups”, has good knowledge, respect, and recognition of both patients and health care system. Jezewski (1993) suggests that nurses have the “attributes necessary for the brokering role” (p. 80). Unarguably, nurses have the potentials to develop skills required for culture brokering. The education, the knowledge, and the communication skills that already discussed in this paper as supporting factors for advocacy actions, can also facilitate developing the skills of culture broker.

As culture brokers, nurses can facilitate communication between patients and other health professionals. This is an act of advocacy that nurses are relatively familiar

with and practice on a daily basis. Similar to my experiences with culture brokering, one study by O'Connor and Kelly (2005) showed that the most vivid characterization of advocacy for nurses was “bridging the gap” between patients and others (p. 462).

***Assessing patients' needs for the information.***

As discussed earlier, the only way to know patients' needs for information is to assess. Croot (1997) and Oberle and Raffin (2009) present models that I find useful in assessing patients' needs for information about their diagnosis or prognosis. I have taken the themes in these guidelines to create a preliminary Assessment of Patients' Needs for Information guideline that can be potentially used in BCCA nursing guideline (Appendix A).

Oberle and Raffin (2009) suggest that in some ethical situations, “nursing obligations are often unclear, and a nurse' freedom to act in the most ethical manner is not always guaranteed” (p. 69). In order to support nurses in finding approaches to ethical problems, Oberle and Raffin (2009) offer a model that provides “questions for ethical reflection” (p. 69). This model has been presented in the CNA Code of Ethics (2008) as a “useful tool to guide nurses in their thinking about a particular issue or question” (p. 36). “Questions for ethical reflection” suggested by Oberle and Raffin (2009, p. 69) includes five sections containing a series of questions that would address the objective of that section. These sections include: “1) understanding the ethics of the situation: relationships, goals, beliefs, and values; 2) reflecting on the range of available choices; 3) maximizing the good; 4) taking ethical action; and 5) reflecting on and reviewing an ethical action” (Oberle and Raffin, 2009, pp. 70-71).

Similarly Croot (1997) has introduced a guideline for truth telling that can be incorporated into the Oberle and Raffin model (2009). Croot's guidelines (1997) would add steps such as securing the facts, determining if the time is right, making time and place, asking patients, telling and listening, preserving hope, and follow-up.

***Managing the risks of advocacy.***

Considering potential risks may be a major factor in nurses' reluctance in practicing advocacy for truth telling. However, as the authors in the literature suggest, considering and assessing the risks of advocacy in an important step in creating strategies for managing those risks (Doust, 1997; Kohnke, 1982b; Lancaster, 1986; Mallik, 1997a). Snowball's (1995) study showed that nurses did not necessarily mind having a little bit of conflict with others and thought that would challenge people and would result in some good changes. Regardless of how we view and feel about the risks of advocacy, they exist and need our attention and preparation. Some of the strategies in dealing with risks, that are discussed in the literature reviewed for this paper, include knowledge of system and people (Kohnke, 1982b; O'Connor & Kelly, 2005), Good communication skills (Bu & Jezewski, 2007; Mallik, 1997a; O'Connor & Kelly, 2005), and adhering to nursing practice guidelines and Code of Ethics (Canadian Nurses Association's Code of Ethics, 2008; International Council of Nurses' Code of Ethics, 2006; College of Registered Nurses of British Columbia, 2005).

Kohnke (1982b) suggests that knowing the people that are involved in advocacy action and knowing the health care system would help nurses to face the hazards of advocacy. According to Kohnke (1982b), nurses should assess the situation before initiating the advocacy actions and try to gain as much information as possible to

minimize the risks and maximize the benefits of their actions. The assessment tool that I have presented in this paper (Appendix A) has outlined a practical and detailed model to assess not only patients' needs for information but also the context and people who are involved in these situations.

Bu & Jezewski (2007), Mallik (1997a), and O'Connor & Kelly (2005) emphasize on the importance of communication skills in lessening the risks of advocacy and increasing the strengths in negotiating patients' needs. Communication skills are necessary to evaluate patients' needs for information, families' concerns and wishes in terms of disclosure, and the health professionals' attitudes and values about truth telling. In the lights of such understandings, new strategies can be created, sometimes collaboratively, to address patients' needs for knowing about diagnosis and prognosis. This may prevent conflict and in some cases legal actions against the nurse advocate.

The nursing standards of practice and Code of Ethics provide guidelines for advocacy actions and respecting patients' needs for the information about their conditions (Canadian Nurses Association's Code of Ethics, 2008; International Council of Nurses' Code of Ethics, 2006; College of Registered Nurses of British Columbia, 2005). Complying with these guidelines is required of nurses and would strengthen their advocacy actions.

***Collaborative advocacy.***

In my experience, collaboration between nurses, other health professionals and sometimes families, improves our abilities in providing care for patients. According to Donovan (1989) collaboration between health professionals serves patients' best interests and nurses are in the best place to facilitate such collaboration. No matter how

knowledgeable and resourceful nurses are, they may not be able to advocate for truth telling without cooperation with other health professionals. Some aspects of collaboration may involve assessment of the truth telling issue, considering different approaches, taking action, and evaluation of the results (Bu & Jezewski, 2007; Salladay, 2008). As it was explained in the last section, collaboration can maximize the benefit of advocacy and reduce the risks of conflict.

On the other hand, the necessity of collaboration may limit nurses' abilities to advocate if nurses are unable to gain the cooperation of their colleagues and other health professionals in advocacy situations. Nurses may not wish to challenge other care team members in an effort to preserve collaboration. I suggest that in these situations nurses can be creative and negotiate patients' needs with health professionals in order to gain their support. For example the nurse can start a process of advocacy actions that, at the beginning, may not need collaboration with other health professionals. These actions may include assessment of patients' needs for information about their diagnosis and prognosis and the assessment of families' understandings and concerns about truth telling. The results of this assessment can be then communicated to colleagues and other health professionals in order to gain their understanding and support of patients' needs. This is compatible with the culture brokering model that is suggested by Jezewski (1993), where the nurse, as a culture broker bridges the gap between the understandings and values of patients, families, and other health professionals.

### **Research.**

In the process of my literature search for this project, I found a large number of articles about truth telling and a large number on advocacy. However, the subject of

advocacy in truth telling about diagnosis or prognosis is not widely and exclusively discussed. My literature search revealed that most articles on advocacy in truth telling are about consumer advocacy and the patient's bill of rights or whistle blowing. Although themes of advocacy in truth telling about diagnosis or prognosis can be found in the advocacy literature and vice versa, it is important to address the relevance of these two subjects more closely. As Negarandeh et al. (2008) suggest the research on advocacy, its types, nature, and risks, is necessary if we expect nurses to advocate for patients.

From the gap I noticed in the current literature, I suggest that more empirical and theoretical research is needed to further understand the attitudes and beliefs of nurses, nurse leaders, patients, and families about advocacy in telling the truth to patients about diagnosis or prognosis.

Quantitative and qualitative research can explore nurses' attitudes, understanding, experiences, and practices. The results of this research can show the strengths and limitations of nurses' capabilities and understanding of advocacy and be a foundation for education and support. Nurse leaders' attitudes and practices in supporting staff nurses in advocating for truth telling is as important as the attitudes of nurses.

Patients are at the center of the focus for advocacy for truth telling and determine how, when, and how much of the truth they wish to obtain. Understanding what patients count as advocacy for truth telling is of great importance to planning and strategizing for advocacy actions. However, there is a scant amount of literature on patients' attitudes about advocacy. I suggest that qualitative and quantitative research on cancer patients about their understanding, expectations, and suggestions, be planned for future nursing

research. Similarly families' attitudes and understanding about truth telling are important factors in supporting patients' wishes for knowing the truth and need to be explored.

### **Conclusion**

Advocacy in truth telling is an action-filled and patient-focused process that involves providing opportunities for patients to gain the information pertained to their decision making and supporting those decisions. Although the advocacy can potentially be undertaken by any health professional or even by a family member, nurses may be placed in the best position to advocate for patients' needs for truth because of their unique relationship with patients and their role in patient care. Supporting factors such as knowledge, power, communication skills, and leaders' support can further enhance nurses' abilities in advocating for truth telling.

Advocacy for truth telling, however, can be complex, risky, ambiguous, and exhausting. Furthermore lack of role clarity, conflicts, and lack of support of health care system can diminish nurses' desires for enacting advocacy. However these hindering factors should not prevent nurses from advocating for their patients, but should be recognized and managed by education and strategies.

Advocacy in truth telling is an important nursing issue that has not been adequately addressed in the nursing literature. Much attention is needed in raising awareness about the nursing role in advocacy for truth telling, education, strategy creation, and nursing empirical and theoretical research.

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## **Appendix A**

### **Assessment of Patients' Needs for the Truth**

I have designed this preliminary assessment tool to help nurses assess patients' needs for information as well as the environment in which the truth telling would occur. This environment includes time, place, and the people who are involved in the process of truth telling. This assessment is divided into five sections: securing the facts, available choices, maximizing the good, taking action, and reflection/review.

#### **Securing the Facts**

- Do I know enough about patient's medical, cultural, and psychosocial situation?
- Do I know what supports me advocating for truth telling.
- What are my own values in this situation?
- What are the values of all those involved?
- What are the goals people hope to achieve?
- What do others consider to be a good outcome?
- What is the level of knowledge of the persons receiving care or in need of care?
- What information do they need?
- What are the relationships within the family of the person receiving care or in need of care and between the family and health care providers?
- What value differences exist among the caregivers and those receiving care or in need of care?

**Available Choices**

- When is the right time for offering the information to patient?
- Where is the best place for discussing the information with patient?
- What are the preferences of patients and families in related to communication?
- What will help individuals and families clarify what they think will do the most good for their situation?
- What do other health care providers think is best?
- What might be the effects of the various choices?
- What economic, political, legal, institutional and cultural factors are at play in the person's health situation?
- What options require further information and discussion?

**Maximizing the Good**

- Can ways be found to respect the wishes of the person receiving care or in need of care, while keeping the needs of others in mind?
- What might prevent nurses from advocating for truth telling?
- Will the nurses and other health care providers be supported in taking action?

**Taking Action**

- What are my assumptions in this situation?
- Do I know how to ask patient about his/her desires for knowing the truth?
- What are my listening skills and how can I improve them?

- How do I show compassion?
- How can I preserve hope?

**Reflection and Review**

- How can I review the process?
- How can I review the outcome?
- How was everyone affected
- Was there any harm?