Contribution of the pivot nurse in oncology to the experience of receiving a diagnosis of cancer by the patient and their loved ones

by Irène Leboeuf, Dominique Lachapelle, Sylvie Dubois, and Catherine Genest

Abstract
The announcement of a cancer diagnosis represents a difficult situation for the patient, their loved ones and professionals (Reich, Vennin & Belkacémie, 2008). Until now, few studies have described nurses’ contribution to this critical moment along the care trajectory (Tobin, 2012) and even fewer, the contribution of the pivot nurse in oncology (OPN) or infirmière pivot en oncologie (PNO) as this specialist is called in Quebec. This study aims to document the OPN’s contribution to the cancer experience of the patient and their loved ones, from the time the diagnosis is communicated to the period immediately following (four to six weeks). Fourteen PNOs from a Montreal university health centre took part in two individual interviews. Results show that PNOs offer personalized support which draws on their expertise to better understand the experience lived by patients and their loved ones, and adapt their interventions according to their needs and the timing of these interventions. These results support issuing three recommendations for nursing practice in the areas of PNOs: development of expertise, interprofessional collaboration and environment.

Key words: Pivot nurse in oncology, infirmière pivot en oncologie, nursing contribution, announcement of diagnosis, cancer

The issue
Announcing bad news is defined as communicating information that changes the patient’s perception of their health, radically and negatively, particularly at the time of a cancer diagnosis or in case of treatment failure (Buckman, 1984). This situation can bring on a feeling of emotional distress in the patient and their loved ones (DLCC, 2011; Tobin & Begley, 2008), as well as a challenging situation for healthcare professionals (Stiefel & Krenz, 2013; Lehto, 2012).

Indeed, both the nurse and physician are often ill prepared to make the announcement as they have to deal with their own emotions, their less than optimal communication skills and the reactions of the patient and their significant others (Buckman, 1984; Dias, Chabner, Lynch, & Pensio, 2003; Tobin & Begley, 2008; Tobin, 2012). However, studies regarding the communication of information about the cancer diagnosis describe mainly the medical perspective, not that of nurses (Warmock, Tod, Foster & Soreny, 2010; Paul, Clinton-McHarg, Sanson-Fisher, Douglas, & Webb, 2009; Randall & Wearn, 2005) and even less that of pivot nurses in oncology (PNOs).

Moreover, researchers have been trying for over two decades to highlight the favorable context-related elements when announcing a diagnosis. However, scientific evidence has not been finalized regarding the quantity and quality of the required information, the role of the attendant, the type of support and the communication approach (Lockhart, Dossier, Cruickshank, & Kennedy, 2007; Paul et al., 2009; Randall & Wearn, 2005). It has been stressed, however, that high quality communication helps healthcare professionals establish a relationship of trust (Bettevy, Dufranc, & Hofmann, 2006) while reducing anxiety and uncertainty (Delbanco & Gerteis, 2013). It also facilitates the teaching, the flow of information and the development of the treatment plan (Swanson & Koch, 2010; Radziewick & Baile, 2001), while influencing the patients’ perception regarding the care they receive (Eid, Petty, Hutchins, & Thompson, 2009; Randall & Wearn, 2005), hope, psychosocial adjustment (Randall & Wearn, 2005) and decision making (Rassin, Levy, Schwartz, & Silner, 2006).

On the contrary, a sub-optimal announcement of bad news engenders patient stress, anxiety, distress, coping problems, dissatisfaction, reduced quality of life (Eid et al., 2009; Paul et al., 2009) and uncertainty (Mystakidou et al., 2004). Caplan (1964) emphasizes that such a crisis situation is a transition period which lasts from four to six weeks. Caplan's crisis theory (1964) specifies the importance of giving support when an individual experiences a loss in connection with a stressful event in order to restore a state of equilibrium fairly quickly. According to him, the first four to six weeks following the communication of diagnosis are hard to live through, both for the patient and their significant others. Caplan characterizes this step as a crisis that wears off as they develop their adjustment potential to the situation. Anxiety, fear, demoralization and anger are the emotions experienced by the patients and their loved ones during the period following the announcement. These have been reported by several other authors (Campbell, Craig, Egeert & Bailey-Dorton, 2010; Delbanco & Gerteis, 2013). It is in this highly emotional context that PNOs provide information to better equip patients and their loved ones to face cancer and their upcoming treatments.

1. PNO: a specialist integrated within a cancer control interdisplinary team who has the necessary skills to assess the needs of the individual living with cancer and their loved ones (DLCC, 2008, p. 5).

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Some studies bring to light the positive contribution made by the nurse during the announcement (Dunniece & Slevin, 2000; McCulloch, 2004). Although interesting from the perspective of nursing support, these studies do not specify which interventions are the most helpful for the patient and their significant others, from the nursing standpoint. The assessment of France’s Cancer Plan (Plan cancer) for 2009–2013 and 2003–2007 (Institut National du cancer, 2009) reveals that the nurse’s contribution promotes among other things the patient’s compliance with the various therapeutic steps suggested (Smutek, 2006; Thibault & Arbonés-Hérédia, 2009; Tivoli, Sanchez, B., Tardieu, S., Metellus, P., Sambuc, R., & Chinot, 2003) and reduces the length of the second medical consultation (Tivoli et al., 2005). Although this study supports the strategic role of the nurse, it is confined to a medical and organizational perspective of the outcome (compliance and efficiency) and does not really explain the nurse’s ability to help the patient and their loved ones.

Closer to home, the Quebec Cancer Control Council (Conseil québécois de lutte contre le cancer) issued this final recommendation: the implementation of the PNO role and access by any individual diagnosed with cancer, within 48 hours of the announcement (De Serres & Beauchênes, 2000). According to the Quebec Cancer Control Branch (Direction de la lutte contre le cancer ou DLCC) (2008), the PNO is a “[...] resource person from the moment the diagnosis has been communicated and along the entire care and service continuum, including all of the treatments.” (DLCC, 2008, p. 6). The key functions are: 1) Assessing the biopsychosocial and spiritual needs and coping skills of the patient and their family, 2) Educating and informing on the nature of the problems at hand, the impact on the family, the implications of the illness, and the resources, 3) Supporting the patient and family members to promote a sense of well-being within the family, and, 4) Coordinating services. The therapeutic relationship is vital to these functions, and the Calgary Family Systems Approach model (DLCC, 2007) underlies nursing interventions. It is worth noting that up to now there is little documentation on the performance of the PNO’s various functions.

**Purpose**

The purpose of our continuous improvement process is to document the PNO’s contribution to the experience of the cancer diagnosis announcement and the period immediately following (four to six weeks) by the patient and their significant others.

**Methodology**

**Theoretical framework**

In keeping with the Calgary Family Systems Approach (Wright and Leahey, 2009), the theoretical framework titled “conceptual model for cancer patient navigation” or simply Professional Navigation Framework will guide the performance of this study and the interpretation of its results (Fillion, Cook, Veillette, Aubin, de Serres, Rainville, Fitch, & Doll, 2012). This framework describes two interrelated dimensions of the PNO role: one focusing on the health care system and the other on the patient.

**Participants**

This is a descriptive qualitative study in which the accrual of participants, data coding and result analysis took place between January 2012 and May 2013. Fourteen (14) PNOs, whose functions and activities meet the DLCC (2003) criteria, were recruited in a Montreal university health centre.

**Data collection**

After signing a participation form, each PNO met twice with the researchers to share her experiences about two patients (who had received their diagnosis at least six weeks beforehand). A minimum interval of one week was observed between the two interviews. Each PNO was also asked to complete a sociodemographic questionnaire as well as a form requiring her to describe the training received upon hiring or in-service such as the family systems nursing approach (Wright & Leahey, 2009). A semi-structured interview guide was also developed around three themes: support, context and interventions of the PNO at the time the diagnosis is announced and post-announcement. These themes were identified in articles about the PNO’s role and family systems approach.

**Data analysis**

A content analysis performed with the help of the QDA Miner version 3.2 transcript analysis software helped identify the various themes characterizing the health centre PNO contribution when the cancer diagnosis was communicated and during follow-up. The analysis was completed in three stages: 1) data summary (reduction, coding), 2) data presentation, and 3) formulation and verification of findings (Miles & Huberman; 2003). This process helped cross-reference the links between interview transcriptions or parts thereof and the three research themes.

**Results**

**Sociodemographic data**

The participating PNOs were 37.64 years (±9.58) old on average, and their nursing experience and completed training are presented in Table 1.

**At time of announcement (0-48h)**

Regarding the elements related to support and interventions, the majority of PNOs (n = 11) state that they play an important support role in establishing a relationship of trust with the patient and their family from this key moment of the trajectory of care. However, only five PNOs are present at the time the diagnosis is communicated and those who are not included then (n = 6/9) say that this relationship of trust could be facilitated by their presence at the announcement.

From the PNOs’ perspective, the other aspects of their role are informing and clarifying information for the patient and their loved ones (n = 8), coordinating care and services (n = 7) and assessing biopsychosocial and spiritual needs (n = 5). Their support is individualized; they tell of adapting their interventions and providing

| Table 1: PNOs experience and completed training |
|-----------------------------------------------|
| Education level                               |
| Bachelor = 78.6%                              |
| Post-graduate degree = 14.3%                  |
| MSc = 7.1%                                    |
| Nursing experience                            |
| 1-5 years = 14.3%                             |
| 11-15 years = 14.3%                           |
| > 15 years = 35.7%                            |
| Experience as a PNO                           |
| < 6 months = 7.1%                             |
| 13-24 months = 14.3%                          |
| > 37-48 months = 21.4%                        |
| > 49-60 months = 35.7%                        |
| Training in Family systems approach           |
| During their studies:                         |
| 60.0%                                         |
| Upon obtaining their PNO position:            |
| 13.3%                                         |
| In-service:                                   |
| * at their health centre 21.4%                |
| * during clinical/administrative meetings 42.9%|
| * at university seminars 14.3%                 |
| * at pre-conference training 21.4%            |
| * at conferences 21.4%                        |

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support in response to the needs expressed by the patient and their loved ones. These refer to possible interventions considered necessary by the PNO while taking into account the patient's uniqueness: "Of course that at the time of diagnosis people are often sort of stunned, so listening is the intervention I would use the most, to check what their fears are, demystify what the physician said and what the patient understood. (…) Often, it is a matter of letting them verbalize." (Participant 4).

Some elements related to the context facilitate the PNO role if they are present at the time the diagnosis is announced (0-48h). The main elements are: 1) a loved one being in attendance; 2) the relationship of trust with the PNO; 3) a patient who has a pretty good idea of what their health status is; 4) the presence of the PNO; 5) a private location for the announcement; 6) a patient responsive to the assistance being offered; 7) a physician with a humanistic approach.

**Four to six weeks after the announcement**

While the communication of diagnosis is perceived as a shock and a tragedy, the emotional component can be as difficult in the period following, especially when the treatments are started. Several participants mentioned treatment related anxiety and fear of complications and side effects: "First there is the communication of the diagnosis which is a shock and then the patients go through another phase, it is the fear of treatments, how they are going to react, their whole life is changing around the treatments, the family organization, the social organization at work, also everything that is connected to managing side effects, this great unknown" (Participant 11).

After the diagnosis has been announced, the support provided and interventions completed are mostly done on a direct face-to-face basis with the patient and through telephone contact (n = 10). PNOs have to manage various emotional distress reactions on the part of the patient and their loved ones. Here again, the elements related to support and interventions are similar to those described previously for the diagnosis communication. PNOs asked open or systemic questions to explore stressors, the impact the diagnosis announcement had on the significant others and the impact on body image. They recognized it while avoiding making it banal. As some PNOs indicate that one should not overload the patient with information at the time of diagnosis, the post-announcement period is the time for the information, teaching and organization of care aspect. PNOs explain to the patient and their family the upcoming care, treatment plan and appointments they will have.

To optimize symptom management along the trajectory of care, PNOs (n = 13) use the relationship of trust they established with the patient and their loved ones thus promoting their empowerment: “To me, it is impossible to perform adequate follow-up as a pivot nurse if you don’t know your patient adequately, if you did not create a relationship of trust from the start or at least from some point on” (Participant 11). Generally speaking, the established relationship of trust helps them to better choose their interventions and support strategies during the post-announcement phase: "No two people are the same; no two people have the exact same needs, the same story. So, if I know them well, I can tailor my assistance" (Participant 11).

Regarding the contextual elements, the presence and support of loved ones appear to be enablers post-announcement by fostering the retention of information. PNOs believe it is important to have a private location to meet the patient and their significant others (n = 5) along the trajectory of care. However, they report a lack of suitable rooms for their meetings with families.

PNOs see the collaboration of interdisciplinary team members as a facilitator for their practice (n = 8), especially the following: other professionals’ positive attitudes, readiness to share, interdisciplinary meetings, interprofessional collaboration, pleasant work climate and accessibility of resources.

**Discussion**

**At time of announcement (0-48h)**

Only five participants indicated being present at the time of diagnosis communication. For these professionals, the time of announcement corresponds to the medical consultation during which the patient receives their diagnosis while the DLCC (2008) defines it as being the period ranging from 0 to 48 hours post-announcement by the physician. This could explain why this number is underestimated as our own analysis shows that nine PNOs are present at communication of diagnosis, i.e. between hours 0 and 48 post-announcement. Moreover, according to the PNOs, the idea of shock at the time of the announcement is perceived by themselves as well as the patients and their loved ones. To our knowledge, few studies have noted this reality which seems to be common to these three groups of stakeholders (Tobin, 2012), despite the existence of several studies about patient and their families, among others (Dias et al., 2003; Leadbeater, 2001).

Regarding whether or not a PNO should be in attendance when the diagnosis is announced, some of them believe that their absence is not necessarily dramatic but think that their presence is useful during the first 48 hours post-announcement. It is worth noting that the PNOs never reported any negative effects in relation with their presence at the time of announcement. Furthermore, they stress that establishing a relationship of trust is a vital element of their practice and that this could be facilitated by their being in attendance at the announcement. This is supported by Smutek (2006) for whom the nursing consultation is a period of time dedicated to the patient and characterized by active listening and the formulation and assessment of the health situation. The objectives are to establish a relationship of trust, demystify the care and help the patient look into the future.

The participants often mentioned the importance of listening to the patients and their families. This enables them to take into account the individuality of patients to determine their support and interventions from the time the diagnosis has been announced. Listening appears to be a key element of the PNOs’ practice, which is also reported as being central to the trajectory of care by Hébert and Fillion (2011a & b).

From a contextual perspective, the presence of loved ones at the time of announcement is the most frequently reported facilitator in this study. It promotes a reduction of stress in the patient who feels more confident. This is supported by several authors (Baile, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000; Buckman, 2005). The presence of loved ones plays a strategic role in psychological and informational support as they can retain the information and review it with the patient. Furthermore, the location where the announcement is made seems to be critical. According to Buckman (2005) and Baile et al. (2000), selecting the right type of place where the bad news is communicated is essential to minimize its impact on the patient and their loved ones. A quiet and private environment is a key component of the Canadian SPIKES protocol (Setting, Perception, Invitation, Knowledge, Empathy, Strategy/Summary) by Buckman (2005) for delivering bad news.

Regarding the PNOs’ role at the time of announcement, the four key functions of the role as formulated by the DLCC (2008) do match: teaching and informing, supporting, assessing the needs of patients and their loved ones and lastly, coordinating services. However, it cannot be said that there is a support or intervention standard as their interventions are focused on and adapted to the changing needs of patients and their loved ones.

**Four to six weeks post-announcement**

While the time of diagnosis announcement is characterized by the PNOs’ active listening, the informational aspect takes priority post-announcement. Documentation and tools provided during this period can help patients understand their illness and retain
and review the information. This is supported by the results of the study by Hébert and Fillion (2011b) where surveyed PNOs and patients underscore the importance of support (both emotional and informational), symptom management and increased need for information.

The PNO’s support and interventions are mainly provided either via the telephone or on a direct face-to-face basis. This enables them to provide a presence, support and availability tailored to the clients needs as reported by Hébert and Fillion (2011b). Regarding telephone contacts, several studies (Cox & Wilson, 2003; Cox, Wilson Health, Collier, Jones & Johnston, 2006; Overend, Khoo, Delorme, Krause, Avanessian, & Saltman, 2008) stressed that specialized oncology nurses provide the patients with effective and safe follow-up.

The individuality of the patient appears to be at the core of the PNO’s interventions and support. Duhamel (2007) and Wright & Leahey (2009) focus extensively on this notion of uniqueness and multi-realities in patients facing a health issue. According to them, the nurse does not implement a directional intervention inviting instead the patient and their family or significant others to think about ideas and find their own solutions. The fact that the PNOs who participated in this study tend to respect the patient’s individuality in their interventions may be explained by the training they received in the Calgary Family Systems Approach (Wright and Leahey, 2009).

Just as it was at the time the announcement of the diagnosis was made, access to adequate places to meet the patient and their loved ones across the care trajectory is a key element throughout the post-announcement period (Buckman, 2005; Ptacek & Ptacek, 2001). As a matter of fact, the participants indicated a lack of adequate places, insuring among other things interruption-free interviews.

One last important element is the synergy within the team. Indeed, optimal team collaboration appears to be a facilitator for PNOs because it enables the sharing of information and observations about the patients’ health status with other professionals. The DLCC (2005) speaks of reconciliation of knowledge as opposed to confrontation of knowledge. When the other health professionals are present, PNOs feel supported and may experience less stress (DLCC, 2005). Depending on the needs assessments they complete, PNOs can call for the intervention of appropriate professionals or offer the patient the services that can provide him or her with optimal support. Regarding this latter point, one must note the role of pivot played by these specialized oncology nurses as described by the DLCC (2008).

Conclusion

Based on these results, one observes that PNOs have the desire to support the patient and their loved ones in a fair and humanist manner. To them, the relationship of trust is the sine qua non condition to support the person in an individualized fashion that respects their uniqueness across the care trajectory. PNOs thus use their expertise to gain a better understanding of the patient and their significant others’ experience and tailor their interventions. At the time surrounding the communication of diagnosis, when the patient and their family are in a state of shock, PNOs focus on active listening and needs assessment. They stress the importance of having a loved one present at this time for better psychological support and better retention and review of the information supplied. During the post-announcement period, PNOs focus their interventions on the sharing of information and answering the questions from patients and their families while continuing with their support and active listening. Furthermore, their assessment enables the proper coordination of services involving the interdisciplinary team, which seems to be the best response to the patients’ needs while providing the PNOs with optimal support. Lastly, PNOs report that access to appropriate places—a quiet and private environment—is an important element for their follow-up both at the time of announcement and across the care trajectory.

The above study findings lead to the following recommendations for nursing practice: 1) strengthening the expertise of PNOs by implementing co-development meetings on topics such as family approach, distress, and the delivery of bad news; 2) strengthening interprofessional collaboration within interdisciplinary teams by highlighting the roles of the various professionals; 3) Promoting the importance of having adequate places for the meetings with patients and their significant others.

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