



Role of advanced nurse practitioners in the care pathway for children diagnosed with leukemia

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ABSTRACT

Purpose: The development of advanced nursing practices (ANP) can meet challenges presented by evolving needs of health care. We aimed at describing the approach taken to implement ANP in a pediatric oncology-hematology unit.

Method: The Participatory, Evidence-informed, Patient-centered Process for Advanced practice was considered as a conceptual framework for the development, implementation and evaluation of the nursing role. Successive steps were taken for identifying patients and family needs, defining the health care priorities, and establishing a new health care model.

Results: The seven steps of the PEPPA framework were carried out over a year and contributed to the identification of the tasks and the role of the advanced nurse practitioner in the patient care pathway. The implementation of ANP was gradually achieved with the development of new evidenced-based health care procedures. The subsequent approval of a contract specification for advanced nurse practitioners facilitated the onset of a specific consultation, which facilitated a holistic approach.

Conclusion: The impact of the implementation can be appreciated at different levels: i) the patient and his or her family, with improvement of communication and continuity of care; ii) the interdisciplinary team, with development of a dynamic and greater motivation of the health care providers; and iii) the profession, with a greater recognition of the competencies and conceptualization of the new role. An assessment of the process, the structure and the results should be carried out to validate the role of the advanced nurse practitioner throughout the long journey of a child with leukemia.

1. Introduction

The development of new roles, such as advanced nursing practices (ANP), can meet the challenges raised by the continuously evolving needs of patients with chronic diseases. These patients require coordinated care and constant follow-ups in order to improve their outcomes. Knowledge and new competencies acquired by specific academic education allow advanced nurse practitioners to play a major role in the clinical evaluation of patients and follow-up with complex and stable medical conditions (Morin and Eicher, 2012).

Several studies have reported the efficiency and value of ANP in various medical specialties (Kleinpell, 2007; Martin-Misener et al., 2015; Naylor and Kurtzman, 2010). The results of these studies confirm added value to the safety and quality of care, to decreasing morbidity, and to the improvement of quality of life and patient satisfaction

(Donald et al., 2013; Weeks et al., 2016). Moreover, a recent systematic review provided evidence on the importance of including ANP in health care, reporting the best results achieved by a physician-advanced nurse practitioner collaboration rather than by the physician alone (Newhouse et al., 2011). Finally, a financial analysis revealed cost effectiveness and reduced health cost after implementing ANP (Kapu et al., 2014). In pediatric oncology, promising results have been shown with the introduction of advanced nursing practitioners improving patient satisfaction, reducing delay for treatment and cost (Golden, 2014; Vanderway et al., 2017).

A child with acute lymphoblastic leukemia (ALL) faces a complex health care pathway, which includes specific management of both the disease and the long-term follow-up (2 or more years, depending on the therapeutic protocol). This care pathway is characterized by several therapeutic steps that require specific, personalized and individualized

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care. These steps require coordination between the different medical specialties involved in the care of the patient and the family. Moreover, the diagnosis of leukemia is an event that negatively impacts the child's and parents' lives. The parents' role, their responsibilities, the daily functioning of the family group, the roles of the siblings within the family, and the professional life of the parents are negatively impacted, and can generate anxiety, stress, lack of self-confidence and uncertainty (Rodgers et al., 2016). During the health care pathway, parents benefit from acquiring or reinforcing their resilience competences to manage their child's disease (Eilertsen et al., 2016).

Therefore, in agreement with the recommendations of the Scientific Societies (Borras et al., 2014), ANP facilitate improvements along this complex health care pathway. The clinical expertise and the specific competencies of an advanced nurse practitioner play a major role in ensuring continuity of high-quality care and an integrated psychosocial approach. In this context, and in consideration of the specific needs of cancer patients and their families, it becomes crucial that health care institutions define a new model of health care based on advanced clinical practice. In Switzerland, the role of advanced nurse practitioners is developing despite the lack of legal recognition within health institutions (Bryant-Lukosius et al., 2016) and shows promising results in cancer care (Serena et al., 2015).

We aim to describe the steps leading to the implementation of ANP in a pediatric hematology unit. This process was based on the Participatory, Evidence-informed, Patient-centered Process for Advanced (PEPPA) practice as a conceptual framework for developing, implementing and evaluating the APN roles based on patient needs in practice settings (Bryant-Lukosius and Dicenso, 2004). By using such a framework, our goals were to optimize the safety and quality of care for children with ALL, to promote a collaborative and rigorous implementation process and to use a holistic approach along the complex health care pathway.

2. Methods

From February 2015 to February 2016, seven out of the nine steps of the PEPPA (Bryant-Lukosius and Dicenso, 2004) framework were used as the main concept for the implementation of ANP in the Pediatric Oncology and Hematology Unit at the University Hospitals of Geneva. The steps were as follows:

- a) Step 1: Define the target population: children diagnosed with ALL. This step consisted in decrypting the health pathway of the child and his or her parents, starting with diagnosis of the disease, to describe the ongoing pathway.
- b) Step 2: Identify all the acting health care providers and inviting them to participate on one of the following levels:
 - Micro-level: leading health providers, whose roles influence and facilitate the implementation of the ANP in the specific practice setting
 - Meso-level: acting health providers who have a role in defining the profile of the advanced nurse practitioner
- c) Step 3: Analyze the strengths and weaknesses of the current health system in an attempt to identify the improvements necessary for a better health care model. Following approval from the Ethics Committee (No 14-013), a prospective observational study was conducted on children diagnosed with leukemia, their parents and the medical and nursing teams. Questionnaires were followed by semi-structured interviews with the parents. A report was issued and included a comparison between documented observations and international recommendations.
- d) Step 4: Identify the priority health care problems that need to be addressed. To achieve this goal, several strategies were developed. First, a cause-and-effect diagram identified the unmet care needs of children with leukemia, while taking into account the context, the clinical practice and the required care. Second, focus groups and

individual interviews with the medical team, social workers, allied health professionals and nurses collected the various stand-points and perspectives about topics that needed to be addressed. The focus groups were facilitated using the Metaplan technique, which allows to obtain ideas from a group of experts. A facilitator asks previously established questions and each participant write their answer on notecards (McKee, 1993). With this consensus method each participant has the opportunity to express their views while visualizing the topics identified by the whole group and discuss the point of dissent. After obtaining oral consent from each participant, the three focus groups (with six to twelve participants) and the ten semi-structured individual interviews were recorded and transcribed anonymously.

- e) Step 5: Define a new health care model and the role of advanced nurse practitioners in this model. The method for defining the model was based on guidelines from the European Societies (Borras et al., 2014) and the Association of Pediatric Hematology/Oncology Nurses (APHON) (Kline, 2014) as well as a literature review on the standards and competencies of advanced nurse practitioners (Hollis, 2005; van den Hoed-Heerschop, 2005). The definition of the advanced nurse practitioner role was based on the seven competencies of ANP described by Hamric et al. (2013). These competencies include direct clinical practice, guidance and coaching, nurse consultation, ethical positioning, interdisciplinary collaboration, leadership and development of evidence-based practices.
- f) Step 6: Implement the various strategies. Beginning in February 2016, the implementation took place in two phases: 1) information and education of the medical and nursing teams about the new health care model and the advanced nurse practitioner's role, 2) development and implementation of the advanced practice nursing role with the introduction of a nursing consultation, coordination of care during the intrathecal chemotherapy and with various stakeholders in the institution and the community, such as school staff, siblings, social workers, community health nurses and other health care providers.
- g) Step 7: Ensure that all aspects of the role of advanced nurse practitioner are implemented by continually communicating and re-focusing on the health care priorities. Moreover, the collaborations between administrative personnel and the principal health care providers were defined during this step.

3. Results

3.1. Step 1: define patient population and describe current model of care

The incidence of children diagnosed with ALL is the highest among those who are admitted to the oncology/hematology unit of our facility. Thus, this project was focused on this patient population, which is the most common malignancy in children. Fig. 1 summarizes the identified clinical pathway that children with ALL follow during their treatments. As described in these figures, after an initial one month of hospitalization following diagnosis, children are followed on an outpatient basis with short to medium periods of hospitalization in case of intravenous chemotherapy or occurrence of complications such as febrile neutropenia.

3.2. Step 2: identify stakeholders and recruit participants

Fig. 2 summarizes the role of health care providers participating in the new health care model. All these health care players are engaged in the identification of the profile of the advanced nurse practitioner. The members intervening on a micro level are the following: nurse hierarchy, the nurse manager in the unit and in the Department of Pediatrics, health care management, and the medical head of the unit.

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