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The Specialist Palliative Care Nurses' in an Italian Hospital: role, competences, and activities

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Abstract. *Background and aim of the work:* Many authors tried to clarify the palliative care nurses' role, overall in the home care setting, but little is known in different settings of care. We aim to present a Specialist profile of palliative care (PC) nurses in an Italian hospital-based Palliative Care Unit. *Methods*: With an organizational case study approach, we conducted a literature review on PC nurse's role, and we presented the Specialist PC nurses' profile, describing competences and key related activities. *Results:* Our specialist profile highlights that clinical activities are similar to the experiences described in the literature (symptom assessment and management, communication, interprofessional work), while training and research activities are new fields of interest that it's important to explore and promote, most of all in our country. *Conclusions*: Sustaining the flexibility of the role, being recognized by colleagues and keeping the three dimensions connected are the major challenges: drawing up a specialist palliative care nurses' profile can help the team to better define the role framework in an interdisciplinary context.

Key words: Palliative Care, Hospital Palliative Care Unit, Specialist Palliative Care Nurses, competences, skills, role, activities.

Introduction

Palliative Care Nurses (PCNs) are among the main professionals involved in the complex interventions of Palliative Care (PC) for patients with cancer (1) and other life-threatening diseases. The PCN's role requires advanced competences, which are necessary to cope with patients' physical, psycho-social and spiritual needs and organizational issues. In 2013, the European Association for Palliative Care (EAPC) published a white paper on PC training, with the dual objective of proposing a set of internationally shared core competencies and providing a framework for programme development training on PC. The ten core competencies outlined a framework in which all professionals working in the field of PC can be inserted as in table 1 (2).

Many authors have explored the PCN's role in greater depth, highlighting the need to clarify this role and related functions; nevertheless, many studies have been conducted in one particular setting, namely home care. In 2018, Sekse et al. underlined the need for descriptions of the nurse's role in different contexts (3). Furthermore, Hökkä et al. confirmed that research is needed to systematize the nursing competencies for different level of palliative care (4).

While the presence of hospital palliative care units (PCUs) is very common worldwide (5), their presence in Italy is still quite limited despite the large body of wide evidence demonstrating the advantages of early PC intervention (6,7) and the considerable number of patients who die in hospitals (8). PCU hospital-based teams are mainly composed of specialized doctors and nurses who mainly carry out consulting activities for

Table 1. The ten core competencies in palliative care by EAPC White Paper (2)

1.	Apply the core constituents of palliative care in the setting where patients and families are based
2.	Enhance physical comfort throughout patients' disease trajectories
3.	Meet patients' psychological needs
4.	Meet patients' social needs
5.	Meet patients' spiritual needs
6.	Respond to the needs of family carers in relation to short-, medium- and long-term patient care goals
7.	Respond to the challenges of clinical and ethical decision-making in palliative care
8.	Practice comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
9.	Develop interpersonal and communication skills appropriate to palliative care
10.	Practice self-awareness and undergo continuing professional development

inpatients and outpatients (9). They aim to improve quality of life among patients and families, integrating the specialized skills of PC with the skills of other specialists from different hospital wards, ensuring continuity of care and assistance after discharge (10). This article aims to present the Specialist PC nurses' profile in an Italian hospital-based PCU, from its first definition to the current development.

Methods

With an organizational case study approach, we first conducted a literature review on the PC nurse's role, describing what the existing literature shows about Specialist PC nurse in hospital. Then we presented the Specialist PC nurses' profile, describing competencies and key related activities. Lastly, we discussed results, and we proposed some challenges for future research and role development. Analysing the PC nurse profile in light of the existing literature and experiences developed in the field, we intend to contribute to the debate on the role of PCNs in hospitals.

Literature review

We conducted a literature review on the role of the PCN and his/her main daily activities in the hospital setting. The PubMed, Embase, Cinahl, and Scopus databases were searched using the search string [role OR skills OR competence] AND [palliative care OR end of life care] AND [specialist palliative care nurse OR advanced nursing practitioners OR clinical nurse specialist] for English and Italian articles, without time limits. Two authors (A.C., B.E.) revised all records by title and abstract, then they compared results and analysed full-text articles, with the supervision of a third researcher (A.G.).

The search identified 595 records. A total of 114 duplicates were removed, and 459 abstracts were excluded because they were not specific to the PCN or pertained to other care settings (community nurse, hospice nurse, nursing home nurse); additional conference abstracts or articles that evaluated nursing impacts on care outcomes were also excluded. The literature selection process is summarized in the following diagram (Fig. 1).

The full text of 22 articles was analysed and the authors selected 6 articles based on specific and exclusive relevance to the activities of the PCN in the hospital setting. Table 2 describes selected articles, focusing on the main contents.

Few studies, to our knowledge, have examined the PCN's role in the specific field of the hospital care setting. Despite different organizational models and sociocultural contexts, selected articles described the role of PCNs in their field work as very congruent with the roles outlined in the European Guidelines published in the EAPC White Paper. Quantitative studies show that only about 50% of daily activities are addressed to pain and symptoms management as constipation, nausea and vomiting, fatigue and cachexia, difficulty

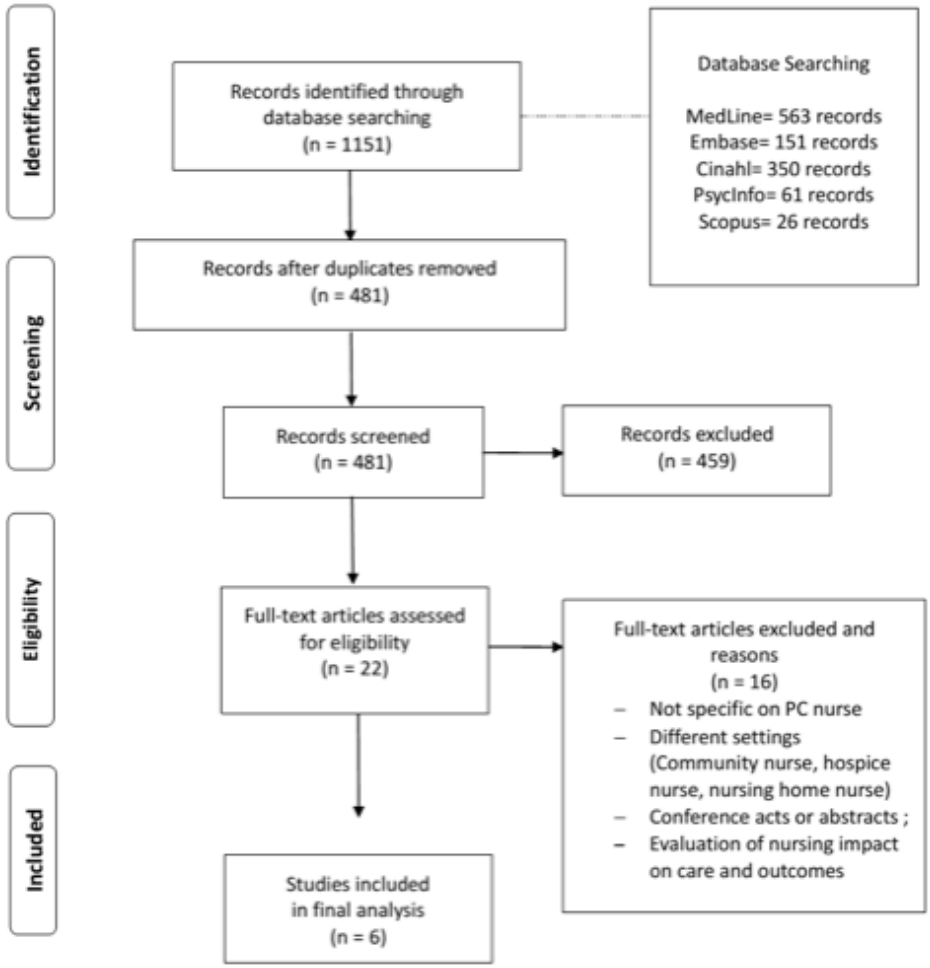

Figure 1. Literature selection diagram

Table 2. Selected full-text article analysis

Author	PC nurse	Setting	Method	Patients assisted	Nurse's activities
Williams and Sidani[11]	N = 1 nurse practitioner (Master's prepared advanced practice nurse)	Palliative ambulatory clinic, southern Ontario (Canada)	Mixed methods (questionnaire, database analysis)	69 cancer outpatients	Patients brought problems related to physical symptoms, incomplete information regarding disease and treatments, psychosocial problems, doubts related to therapeutic choices, practical or economic problems. Main activities: face-to-face or telephone follow-up, symptom management, patient and family education and counselling, coordination of care, maintaining continuity of care. Some specific aspects of the role of these nurses: frequent interchanges with other professionals, patient education/counselling (37.5% of the global time), formal education addressed to colleagues or students, a lack of direct administration of therapies and a lack of participation in medical/surgical manoeuvres. Finally, authors underlined that clinical activity limited the time available for research

Author	PC nurse	Setting	Method	Patients assisted	Nurse's activities
Skilbeck et al.[12]	N=42.9 (full- time equivalent) Macmillan nurses (with advanced competences in clinical, consulting, training, management and research areas)	Generic hospital-based services, community-based services, England (UK)	Quantitative method (collected data on nurses' activities and characteristics of patients)	814 inpatients/ outpatients, died within 6 weeks (40%)	The most common intervention (55% of patients) was emotional care, declined in offering reassurance, listening or interviewing about feelings and emotions. In 21% of cases, the support was also aimed at family members. In 32% and 39% of cases, the intervention was aimed at controlling pain and other symptoms. In general, more face-to-face visits were made with patients and more telephone contact with family members
Georges et al.[15]	N=14 nurses in the PCU	PCU, academic cancer hospital (The Netherlands)	Qualitative method (observation and semi-structured interviews)	Terminal inpatients	Authors distinguish between two different approaches to these patients by nurses. The first—*the striving of nurses to adopt a well-organized and purposeful approach in an academic setting*—highlights a task-oriented approach, characterized by formal language, respect for departmental rules, a sense of self-protection to emotional involvement, and greater attention to the technique and methods of nursing care. The second—*striving to increase the well-being of the patient*—describes an approach more focused on the needs of the patient, favoured by the ability to listen to the problems that arise in the care relationship. The humble attitude, the understanding of the experiences and the capacity for self-reflection allow the nurse to accept complex emotional situations through their presence for the patient
O'Connor et al.[13]	N=21 palliative care nurse consultants (PCNCs)	Tertiary teaching hospitals, Melbourne (Australia)	Quantitative method (collected data on nurses' activities and characteristics of patients)	282 inpatients, cancer (74%), new referrals (73%), time between admission and referrals 6.57 days	In 73% of cases, the PCNC is the first PC professional who interacts with the patient. The main activities concern the following: the management of physical and psycho-social symptoms (40.5%); and the planning of discharge (28.94%), family care (23.5%), and end-of-life care (6.97%). The authors stress that it is difficult to describe and quantify the specific activities of nurses in hospital PCs, particularly for specific aspects such as continuity of care and support for the family, declined in education and counselling
O'Connor and Chapman[16]	N=10 palliative care nurse consultants (PCNCs)	Tertiary teaching hospitals, Melbourne (Australia)	Qualitative method (interviews)	n.a.	The authors evidenced four main contents of nursing work in PC in the hospital: the bond of the various professionals with the patient and the family, being a point of reference between the hospital and local services, "*being responsive*" in interaction with others and having good communication skills, "*being challenged*", facing different challenges such as the continuous redefinition of the role, caring for new types of patients, and having a limited amount of time available

Author	PC nurse	Setting	Method	Patients assisted	Nurse's activities
Csorba[14]	Nurses specialists	Hospitals, Jerusalem (Israel)	Quantitative method (collected data on nurses' activities and characteristics of patients)	Mainly cancer inpatients/ outpatients	The main activities of these nurses are as follows: symptom assessment; education for patients, families and even staff; addressing communication and psychological support issues; collaboration in discharge; some practical activities (pain therapy, thoracentesis, etc.); end-of-life care; and bereavement support

PC, palliative care; PCNC,palliative care nurse consultant; PCU, palliative care unit

sleeping (57% in William et al., 32-39% in Skillbeck et al., 40.5% in O'Connor et al., 24-31% in Csorba). Very often, PC nurses spend time for emotional care, directed both to patients and family members. Authors named it in different ways: education and counseling (11), offering reassurance, listening or interviewing about feelings and emotions (12), management of psychosocial symptoms (13), conversations (14). Terminal care is not the prevalent activity (6.97% in O'Connor et al., 4-12% in Csorba). Other described interventions are: providing advice and information, addressing practical and social help, discharge planning, and coordination of care with other services. Quantitative studies have attempted to quantify the main activities, but some psycho-social/organizational interventions are challenging to include.

Qualitative studies explore the PC nurse role in the hospital through in-depth interviews. Georges et al. described two different approaches that PC nurses have towards patients: the first task-oriented ("*Striving to adopt a well-organized and purposeful approach in an academic setting*"), and the second focused on the needs of patients ("*Striving to increase the well-being of the patient*") (15). O'Connor et al. evidenced four main themes that clarified the PC nurse role: *being the internal link, being the lynch pin, being responsive, and being challenged.* Each participant described the role as blurred and often misunderstood by colleagues, people-centred, and mainly composed of emotional care and educational interventions (16).

Finally, as training skills are largely outlined, research skills are not examined in depth.

The definition of the "competence profile" of PCNs in an Italian hospital

In Reggio Emilia (Italy), the PCU was constituted in 2013 at a 900-bed tertiary cancer research hospital. It has been established as part of a research project on the implementation of an early PC intervention in hospital for advanced cancer patients (17). The PCU is a specialized palliative care unit with no dedicated beds; it assists outpatients and inpatients and offers also basic psychological support. The PCU assists mainly advanced cancer patients with an early palliative care approach. Currently, the team consists of two full-time nurses, a part-time nurse expert in training and three doctors.

In 2014, the PCU team began to define, in collaboration with the Directorate of Health Professions, a "specialist profile of competencies" of the PC nurse in the hospital, starting from the compilation of a "job description" of nursing activities carried out daily. Once the activities were identified, we integrated the profile by referring to the Italian nurse profile, (18) the Italian Deontological Code (19) and the Italian Society of Palliative Care (SICP) "Core Curriculum of the Nurse in Palliative Care" (20) in addition to a basic analysis of the scientific literature.

This profile represented the first experience in defining the skills of the PCNs within the hospital of Reggio Emilia and one of the few in Italy. It is composed of five major areas of competencies and related activities. A summary of this first PC nurse profile is presented in Table 3.

Table 3. Main competences and activities of PCNs in an Italian hospital PCU, elaborated in the first PC nurse's Profile in 2014.

Competences	Activities
Skills associated with the professional values and the nurse's role in palliative care	• Nurse identifies, shares and applies the values and purpose that inspire models and services of the palliative care network.
	• They take care of the patient and his/her family, gathering information from the available sources and through dialogue, empathy and communication skills.
	• They adapt communication to the culture, values, levels of awareness, emotions, desires and clinical and cognitive conditions of the assisted person and his/her family.
	• They take into account the holistic PC needs (physical, psychological, social and spiritual needs), both with inpatients and outpatients.
	• They organize family meetings with the patient and his/her family, with the aim of collecting information, sharing concerns and discussing diagnosis and prognosis, and clarifying the objectives of the treatments.
Skills associated with nursing practice and clinical decision-making to ensure quality of life in palliative care	• They assess and monitor pain and other symptoms with validated scales.
	• They assess, in collaboration with the PCU team, quality of life according to its subjective and multidimensional meanings.
	• They evaluate physical, psychological, social and spiritual reactions to disease, symptoms, treatments, end-of-life care and bereavement.
	• They evaluate, plan and implement with the PCU team the methods to guarantee the most appropriate setting for patient assistance, in compliance with his wishes, social and economic resources, with the collaboration of the various professionals of the PC network.
Skills associated with the appropriateness of interventions, nursing activities and skills and their evaluation to provide optimal care in palliative care	• They evaluate, plan and implement, in conjunction with the PCU team, appropriate interventions for the problems that are proportionate to the needs of the assisted person and his/her family. They also make use of pharmacological or non-pharmacological interventions.
	• They evaluate the effectiveness of interventions and therapeutic prescriptions, both in outpatient settings (by telephone follow-up) and for inpatients (bedside follow-up).
	• They educate and supports the patient and the family in the management of symptoms, therapies and care pathways (side effects, therapeutic goals, awareness of disease).
	• They educate and supports other nurse colleagues in the management of symptoms, therapies and care pathways (side effects, therapeutic goals, awareness of disease).
	• They develop their own continuous training path, evaluating the scientific evidence supporting the best care practices in the palliative care area.
Communicative and interpersonal skills in palliative care	• They evaluate and manage, with the PCU team, the feelings of concern, anxiety, stress, rejection, anger, depression, aggression, helplessness and loneliness experienced by patients and their families.
	• Using dialogue, they help the family achieve realizable goals and develop awareness of illness, incurability and prognosis.
	• They activate and collaborate with other professionals along the care path (e.g., psychologists, cultural mediators).
	• They guarantee continuity of care through communication, documentation, maintenance of information records, IT management and paper systems.
Leadership and management skills of group dynamics in palliative care	• They share information about and the aims of care for patients, participating in weekly team meetings.
	• They participate in research activities during all its phases, collaborating with the other members of the PCU team.
	• They collect data on the daily activities conducted by the PCU team, thus promoting actions directed towards self-reflection and improvement.
	• They design, organize, implement and evaluate training programmes for healthcare personnel within the hospital and among students.

PC, palliative care; PCU, palliative care unit

From the original profile of competencies, between 2013 and 2020, the PCNs' role has evolved due to the following elements: (a) updated findings in the literature; (b) the mission of the PCU, which combines clinical, training and research activities; (c) the development of specialist skills among nurses within an evolving team; and (d) the need to provide increasingly accurate and useful solutions to patients' and family's needs. We now describe the essential elements of current competencies and key related activities of PC nurses in our hospital, dividing them according to the three development macro areas defined by the PCU mission.

1. Macro area: Clinical competencies and activities
   The early activation of PC allows the team to meet cancer patients who are still under chemoradiotherapy treatments and who still have a good level of self-autonomy. Many of them, although in an advanced stage of illness, are engaged in work, have active roles in their family, and still have different choices to make regarding their care pathway. What mainly characterizes the clinical work can be summarized in three macro-areas, described below.
   - *Global assessment and symptom management*
     The assessment of needs is a central element of the work of PCNs and is carried out at the patient's initial presentation and during follow-up. The nurse, who is generally the first person to welcome the patient, explains the principles and goals of PC and explores the patient's current situation using validated tools, such as the Italian versions of the iPOS (21) and ESAS (22). This initial data collection attempts to cover everything that can be useful for the purposes of global management and considers all the aspects that influence quality of life. Moreover, the PC nurse helps the patient to order needs according to his own priorities. The second assessment tool is the follow-up either by phone or face-to-face. This intervention, as the literature suggests (1,23), may include an assessment of physical or psychological symptoms after the introduction of a new therapy or an interview about new information or clinical decisions (e.g., CT results, suspension of treatments). The scheduling of the assessment is not standardized, but it is dictated by the outcomes to be measured. The nurse also collaborates with PCU members in the provision of services such as blood transfusions, paracentesis, rapid titration of opioid therapy, blood drawing and IV drug administration.
   - *Communication and educational competences*
     An important part of nursing activities within the PCU involves interventions in which communication plays a central and crucial role. A significant element of the communicative intervention is the educational activity aimed at the patient or at the patient-caregiver dyad, as suggested by the most recent literature (24). Insufficient or inaccurate information, beliefs or prejudices about prescribed drugs (e.g., opiates) or symptoms related to the disease (for example, fatigue or cachexia) can affect, even significantly, compliance with the proposed therapies and personal experience.
   - *Interprofessional work*
     PC is based on interprofessionality, first between physicians and nurses. In addition to the frequent joint visits, the morning briefing is a formal moment of interchange of information and opinions, aimed at planning visits and at sharing information on patients in care. Nurses are trained also to seek the involvement of other professionals when necessary, sharing information and activating other available resources (psycho-oncologist, social worker, bioethicist, cultural mediator, other specialists). To ensure continuity of care, the PCN collaborates with those involved in other PC services (case manager of departments, home nursing service, etc.). They actively participate in the construction and development of the PC network in collaboration with other local professionals. Interprofessional work is also supported by biweekly meetings and shared training with PCU team members.
2. Macro area: Training activities
   Developing the skills profile, particular attention was paid to the role of education and training, as demonstrated by the inclusion of a training expert nurse in the PCU team.
   The training expert nurse has the task of organizing and supporting all members of the team in the design and implementation of training projects with

evidence-based characteristics (e.g. effectiveness and measurability) (25), both for the PCU team (self-training) and for other hospital professionals and students. The training courses follow the founding principles of adult education, which recommend an experiential teaching methodology focused on training needs and concrete problems that professionals address during clinical practice (learner-centred method) (26).

The advanced skills learned by the PCU professionals are shared with other hospital professionals and students, according to the model of level II (specialists) on level I (non-specialists) education (27). PC nurses take part in the design and implementation of courses for external professionals ("formal education"), though they often support colleagues in other departments with consultations ("informal education"), thus activating what is known as "dissemination" training (28). Some of these training courses have been included in research protocols that evaluate the impact of the training intervention (29-31).

3. Macro area: Research activities

As previously mentioned, PCU in Reggio Emilia is located inside a Scientific Institute for Research, Hospitalisation and Health Care (IRCCS). In this context of care, scientific research is particularly important and developed for any health profession. The research activities, as well as clinical and training activities, follow an interdisciplinary approach. Currently, PCNs collaborate at various levels of responsibility on the drafting of protocols, recruitment and data collection, the analysis of data and the dissemination of results. The research activities are often intertwined with clinical activities; the presence of the patient can become an opportunity to propose a study or to administer assessment scales, or the intervention can become part of the clinical activities. The main lines of research of PCU are described in Table 4.

Discussion

Our PCNs' profile and its development follow the principles described in the literature so far and it is still one of the few experiences of this kind developed in Italy. Our clinical activity is similar to other experiences described in the literature; patient care during the last days of life is a minimum component of daily work, which instead focuses on ensuring continuity, education and empowerment of the patient-caregiver dyad and support in the coping process in the care pathway. We have noticed how the telephone follow-up (FU) tool has, in the short and medium term, a positive impact on the overall management of patients and their families. These interventions contribute to improvements in compliance and adherence to therapies, reduce the caregivers' stress and encourage active participation in the care pathway. Telephone FU is an instrument already described in the literature (23), but it is relatively new in our hospital context, especially if it is used with educational purposes.

Overall, in our experience, the relational component is just as important as the purely technical component. In Great Britain, Seymour J. described the difficulty of Macmillan nurses in reconciling their desire to remain tied to the clinic and the need to move instead towards a role centred more on counselling and education (32).

The hospital setting involves several challenges for the development of the role of PCNs and, in general, for the activities of a PC team. Payne in Great Britain and Sekse in Norway described some of these challenges (33,3); in our experience, we have identified three main

Table 4. Main research lines of the PCU

• Research in training Research focused on evaluating the effectiveness of the training that we deliver to other health professionals on issues such as advanced care planning, communication skills
• Research on care pathways/integrated models Research focused on organizational models for simultaneous and integrated care, together with other specialists (e.g., patients with pulmonary or gastric cancer, haematological patients, and cachexia syndrome).
• Research on PC for non-cancer patients Research focused on palliative care applied in the non-oncological field (e.g., spiritual needs in incurable patients, and relationship of ALS patients with health services).

PCU Palliative Care Unit; ALS Amyotrophic Lateral Sclerosis

challenges which can be considered transversal to the macro areas described above and whose development becomes necessary for a high-level profile:

1. The flexibility of the role.
   The boundaries of the nursing role in PCU must be clear but also flexible (16,34). This flexibility is dictated by some factors:
   - According to the definition, PC are "patient-family centred" and therefore require an effort to adapt the communicative approach, the therapies and the aim of care, taking into account the various levels of complexity and the different outcomes to be evaluated.
   - Nurses' activities vary on a daily basis: they are not always predictable, and they cannot be systematically planned. The ability to be flexible in organizing one's work is fundamental to preventing overwhelm by the diversity of functions and relationships that the nurse must manage (16).
   - The professionals with whom the PCNs interact are multiple, both inside and outside the team. Some Australian PCNs described daily activities as "doing a circle", because they pass from staff to the patient and to his/her family, crossing traditional boundaries in connection with other services (16). The PCNs often interface also with health and social care professionals and managers, policy-makers and planners (33); through comparison with different roles and skills, PCNs can get trained and, at the same time, outline their own professional boundaries among health workers.
2. The recognition of PCNs' professional roles by the hospital colleagues. A qualitative study conducted in Great Britain underlined the importance of the ability to "influence" other professionals, that is stimulate the attention regarding PC needs through education, negotiation/comparison and support (35). Consulting activity is a peculiarity of the palliative nursing role in hospitals, although this role is sometimes poorly recognized by colleagues, often due to the lack of clear understanding of the skills, expertise and role of specialist nurses. Informal "*on-the-job* education" is often present in the clinical activity in our experience, even if few nurses conduct in Italy regular consultancy activities in hospitals.
3. Complexity of keeping the three dimensions connected (clinical, training and research activity). It is challenging to address clinical practice, professional leadership, education and research (34). Working on and growing in all three dimensions requires time and energy. From the beginning, the organization of the local PCU was designed to allow the development of these aims; however, the collaboration among the members of the team becomes fundamental to support the workload and to underline the value of research in daily clinical practice. In our opinion and experience, research activities represent part of the tasks required of PCNs (36); however, in the literature examined, there is a lack of information about the involvement of PCNs in research projects, and it is not clear how research activities are integrated within routine work activities. It is important to combine clinical and research activities because it helps to critically examine clinical practice, outcomes, communicative approaches with patients and families, and organizational models. The article has some limitations. It describes a single case, comparing it with ones in different organizational and social contexts. Furthermore, it lacks quali-quantitative data useful to support and complete the description of the PC nurse role. These issues can be interesting for future research project.

Conclusions

The role of the PCN has particular features in the hospital setting; scientific societies have provided frameworks of advanced competencies, but the literature is still lacking in describing the role of PCNs in hospitals. In our opinion, even in defining a professional role, the scientific literature can be supportive, but it must be adapted to the working context; conversely, field experience can enrich internationally shared literature. This is particularly true for the dynamic and flexible PCN's role, which can be updated over time.

In the Italian context, the drafting of a specialist PCN profile in the hospital has been innovative, and it helped us to better define our role framework in a strongly interdisciplinary setting. For the future, we propose to update the actual PC nurse profile in light

of its evolution and to develop further improvement projects in the definition of specific competencies (e.g., ethical and spiritual competencies). Moreover, the challenge now in Italy is to obtain a regulatory attribution and proper recognition for nurses with advanced skills in PC within local healthcare organizations.

Legends; PC: Palliative Care; PCNs: Palliative Care Nurses; EAPC: European Association for Palliative Care; PCU: Palliative Care Unit; SICP: Società Italiana di Cure Palliative; iPOS: Integrated Palliative Outcome Scale; ESAS: Edmonton Symptom Assessment System; CT: Chemotherapy; i.v.: intravenous; IRCCS: Istituto di Ricovero e Cura a Carattere Scientifico; FU: Follow up; PCNC: Palliative Care Nurse Consultant; ALS: Amyotrophic Lateral Sclerosis

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