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ORIGINAL ARTICLES AND REVIEWS

Training in pediatric palliative care in Italy: still much to do

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Abstract

Aim. This survey investigated the availability of training programs in pediatric palliative care (PPC) for Italian postgraduates specializing in pediatric medicine.

Methods. Two questionnaires were developed: (i) a questionnaire addressed to the Directors of Italian postgraduate pediatric medicine programs (n = 37); and (ii) a survey to the postgraduate students in pediatric medicine at the University Hospitals of Padua and Udine (n = 127).

Results. 14 directors participated (response rate: 37.8%). In 85.7% of cases (n = 12), lectures on PPC were offered, for a supposed maximum of 90 minutes/year. 116 students responded (response rate: 91%): they stated that, approximately 40 min/year of training on PPC was provided. In total, 37% of responders stated they attended a PPC Service during their training. The majority of responders (68.1%, n = 79) did not feel ready to care for a pediatric patient with life-limiting disease.

Conclusions. Although PPC is well-recognized as part of a pediatrician's training, it receives poor attention.

Key words
- education
- pediatric palliative care
- end-of-life
- postgraduate

INTRODUCTION

The number of children diagnosed with life-limiting (LL) and life-threatening diseases is unfortunately high: it has been estimated that 10 per 10 000 children aged 0-19 years suffer from a LL disease, with an annual mortality rate of 1 per 10 000 children aged 1-17 years, and these figures are increasing [1, 2]. Guaranteeing an acceptable quality of life for children with LL diseases is a healthcare priority, and this goal can be achieved with an adequate control of symptoms to be pursued through specific medical competencies, a multidisciplinary approach, proper communication and organizational skills. However, the majority of children with LL diseases present many uncontrolled symptoms; moreover, communication, spiritual and social aspects are frequently not comprised into the care program and often delegated to the patient's family, overall resulting in a reduction in the quality of care [3-5].

Pediatric palliative care (PPC) is the discipline that can respond to spiritual, emotional and relational needs taking care of the child's body, mind and soul, and supporting, at the same time, his/her family [6]. The goal of PPC is to ensure the best quality of life possible for both children affected with a LL disease and their relatives, evaluating all their needs and assessing the risk-benefit balance of each act, procedure and choice, without jeopardizing the efficacy and safety of proposed interventions. Of note, PPC is not the only end-of-life (EOL) care: according to the current model, curative, palliative and bereavement care should coexist for each patient, and one aspect may prevail on the others according to the different phases of the disease course [7]. Despite its importance, PPC is still scantly diffused, and a lot of children with LL diseases have no access to PPC services: for instance, in Italy no more than 5% of children eligible to PPC have actual access to a dedicated service [8].

In order to widen the diffusion of PPC and serve chil-

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dren with the best possible level of care, proper training should be mandatory; however, in Italy, training of healthcare professionals in PPC is incomplete and inadequate thus representing an important barrier to the full implementation of PPC all over the country [9-12]. To our knowledge, detailed information on the PPC training and its diffusion in Italy is not available.

This survey aimed to determine the availability of training programs in PPC and EOL care for Italian postgraduates specializing in Pediatric Medicine and how the knowledge and skills offered as part of their training is structured.

METHODS

Design

A cross-sectional national survey on the attitudes of Italian postgraduate students specializing in pediatrics based on the knowledge and skills in PPC and EOL was conducted from June to August 2017.

In particular, two questionnaires were developed: (i) a questionnaire was sent to the directors of Italian postgraduate pediatric medicine programs; and (ii) an online survey was sent to all the postgraduate students in pediatric medicine at the University Hospitals of Padua and Udine.

The two questionnaires were developed by experts in PPC and professional methodologists in line of a previous similar effort [13]. Pilot versions of the questionnaires were administered to a director of Italian postgraduate pediatric medicine program and to a group of postgraduate students. Feedback was taken into account and critically included in the final versions of both questionnaires by the development committee.

The two questionnaires

The questionnaire for the Pediatric Residency Programs' Directors consisted of 30 questions and was aimed at collecting data and opinions on the organization of training programs regarding pediatric pain therapy and PPC. The second questionnaire consisted of 75 items divided into five categories, and was aimed at collecting social and demographic features (age, sex, year of degree and residency), evaluating the pediatric residents' impressions concerning information received during their training and assessing the actual knowledge of these topics using appropriate questions. Both questionnaires combined dichotomous, multiple choice, demographic and Likert response scale questions with free-text questions. Approximately 20 minutes were necessary to complete each survey.

The survey was conducted using the Google Forms web-based program survey. A link to the survey was sent out to the participants by email together with brief explanation of the aims of the survey. Two reminders were sent to non-responders, and completion of the questionnaire was considered as consent to participate in the study.

Data analysis

Data were analyzed by descriptive statistics using the SAS 9.4 (SAS Institute Inc., Cary, NC, USA) for Windows.

RESULTS

Questionnaire n. 1

A total of 14 directors of Italian postgraduate pediatric medicine programs out of the 37 who were contacted participated in the study, with an overall response rate of 37.8%. Overall, 92.9% (n = 13) rated pain management as "very important" clinical skills. In 85.7% of cases (n = 12), topic lectures dealing with PPC were offered during postgraduate training programs. Moreover, 85.7% (n = 12) offered specific training program in pain management, and 78.6% (n = 11) offered specific training in PPC.

The duration of these lessons ranged between 50 and 90 minutes/year. Resident training in PPC was offered in six different schools (42.9%) but was mandatory only in two cases of PPC-dedicated services. In the other structures, the training period took place at the Pediatric Onco-Hematology Service. In three (21.1%) schools, it was possible to devote the final year of specialization entirely to PPC.

Questionnaire n. 2

- Baseline characteristics

In total, 116 postgraduate students in pediatric medicine completed the survey, with an overall response rate of 91% (116/127). The mean age of the responders was 29 years (standard deviation: 5 years), and 81.9% of them (n = 95) were females. More than one-third of the participants (37.1%, n = 43) attended a period in a PPC service during their residency.

- Level of training

According to the results of this second questionnaire, approximately 40 minutes of training on palliative care (in general), EOL and PPC care was provided in each academic year; only 16.5% (n = 19) of the participants received basic PPC training, and 20.7% (n = 24) of responders did not receive any basic training regarding the above-mentioned fields. Only 15.3% (n = 15) of the responders declared to have received > 6 hours in PPC training during the entire postgraduate course.

Overall, 91.4% (n = 106) of responders indicated PPC as an essential competence for a pediatrician who must actively participate in the care of patients with LL diseases. Only 5.2% of pediatric residents (n = 6) did not agree with this.

- Attendance to a PPC service

In total, 37% of responders (n = 43) revealed they attended a PPC service during their postgraduate training program, in most cases for a period of 16-60 days *(Figure 1)*. In 87.9% (n = 102) of cases, they were involved in the management of a child with complex needs. In total, 12.3% of postgraduate residents (n = 14) dealt with the communication of incurable disease at firsthand, four of them with the supervision of a senior physician; 16.4% (n = 19) of the residents interviewed declared they carried out the communication of a child's death to his/her family, but only in two cases after adequate training.

More than half of participants (58.6%; n = 68) monitored at least one child at EOL care, more frequently in

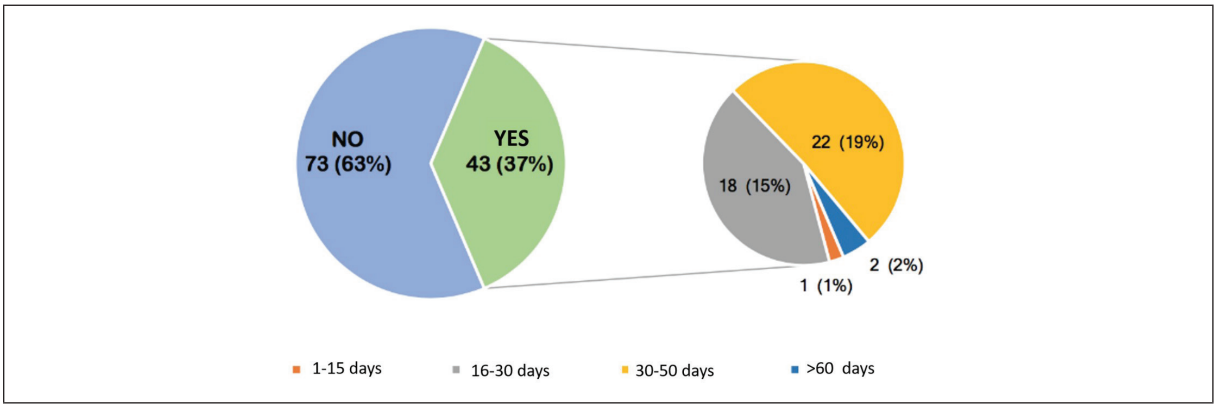

Figure 1
Attendance to a pediatric palliative care (PPC) service.

ICU and Onco-Hematology Service and mostly during the last 2 years of residency, with experience of EOL that increased with the experience and year of postgraduate course *(Figure 2)*.

Regarding management of children' EOL care, respiratory symptoms and pain control were indicated as the most disturbing ones, and pharmacologic treatment with strong opioids and benzodiazepines was considered the most appropriate therapy by approximately half of the responders (52.8%, n = 56).

- Level of knowledge

Almost all of postgraduate students (96.6%, n = 112) correctly defined PPC as *"the care addressed to children with life-limiting and chronic illnesses, who need high levels of care, regardless of the expected survival time"*. In 65.5% of the cases (n = 76), PPC was correctly defined as a care that should start when the diagnosis of incurability is made. Between 90% and 100% of participants denied that PPC necessarily entails the suspension of treatments, that PPC exclusively regards the onco-hematologic field, that the symptoms' control is the only aim of care and that the child's home is the only adequate place to deliver CPC.

Figure 3 shows the percentage of correct answers to the above-mentioned questions: an increase over time, but still suboptimal, rate of correct answers was shown.

In total, 91 postgraduate students (78.4%) properly indicated categories of diseases eligible to PPC and in 12 cases (10.3%) it was stated how the eligibility of a patient to CPC, independently to the specific illness, is highly related to the complexity of care required.

Overall, 33.6% of the responders (n = 39) was aware of local PPC services, while 4.3% (n = 5) had a knowledge of the organizational procedures to dispose for a body of a dead child.

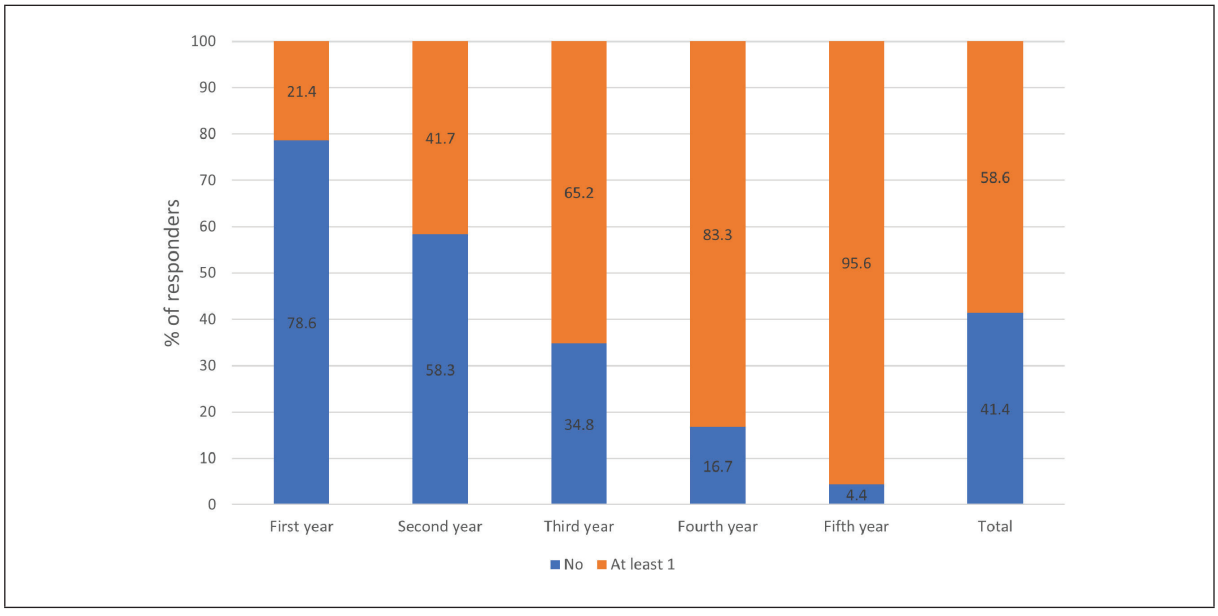

Figure 2
Experience with monitoring of a child at his/her death. All number are expressed as percentages of the total number of responders (n = 116).

• Self-evaluation

The majority of responders (68.1%, n = 79) did not feel ready to care for pediatric patient with a LL disease, 73.2% (n = 85) of the postgraduates interviewed perceived that they did not feel ready to manage a child's EOL care and 63.7% (n = 74) of the respondents considered their skills in PPC and EOL management to be "weak" or "very weak".

Among the 37 postgraduate residents (31.9%) who declared they felt ready to manage a child with a LL illness, 81.1% (n = 30/37) received specific training in PPC and 75.7% (28/37) received specific training in EOL care. On the other hand, 70.2% (26/37) aimed at improving his/her knowledge of PPC, and in particular of bioethical and spiritual issues. Almost all of the respondents (94.8%, n = 109) declared "important" or "very important" to acquire specific knowledge and competence in EOL management during their postgraduate training. A training period in CPC service was associated with increased self-perception of expertise, with more attitude in managing findings of EOL (data not shown).

Three educational approaches were considered as most useful: direct observation of older residents or senior doctors caring for a pediatric patient with a LL disease (judged useful by 85.3% of responders, n = 99); discussion of clinical cases discussion within small multidisciplinary groups (70.7%, n = 82); communication training with standardized patients/families and/or role play (69.8%, n = 81).

DISCUSSION

Only scant information exists on the actual implementation of PPC training. Our survey investigated this issue from two different perspectives, namely pediatric program directors and postgraduate students, with the aim to provide a picture, although limited, of the current status of PPC training in Italy. However, we must point out that only a limited number of responders were collected for each questionnaire, and therefore our data cannot be considered immediately and fully representative of the Italian scenario.

First, the value of PPC as both a clinical competency and as a component of pediatric residency education was well recognized by program directors and postgraduate students, in line with previous studies and with current recommendations that indicate dissemination of PPC as a major unmet clinical need [6, 12, 13]. Although the importance of PPC training was well recognized, only a very limited number of hours was dedicated to PPC and EOL care during the pre- and post-graduate academic course, with only a minority of students (15%) receiving > 6 hours of training and less than 40% of them attending a dedicated PPC service during their residency period. Remarkably, program directors and postgraduate students were not consistent in estimating the number of training hours dedicated to these issues. Moreover, a substantial number of the residents judged their training as inadequate and they did not feel ready to manage either a child with a LL disease or the EOL care of a pediatric patient. However, even if time devoted to CPC training resulted inadequate, a progressive increase in both knowledge and competence from the first to the last year of residency is reported. This finding also suggests an individual effort in the acquisition of more expertise in the field, representing the first step towards focused didactic opportunities.

The poor attention dedicated to PPC and EOL care training reported in Italy, according to the results of our survey, was not totally unexpected, since a low level of medical professionals' training in PPC was already documented in countries other than Italy, partly due to poor dissemination of PPC service, economical and organizational issues, and lack of both formally defined

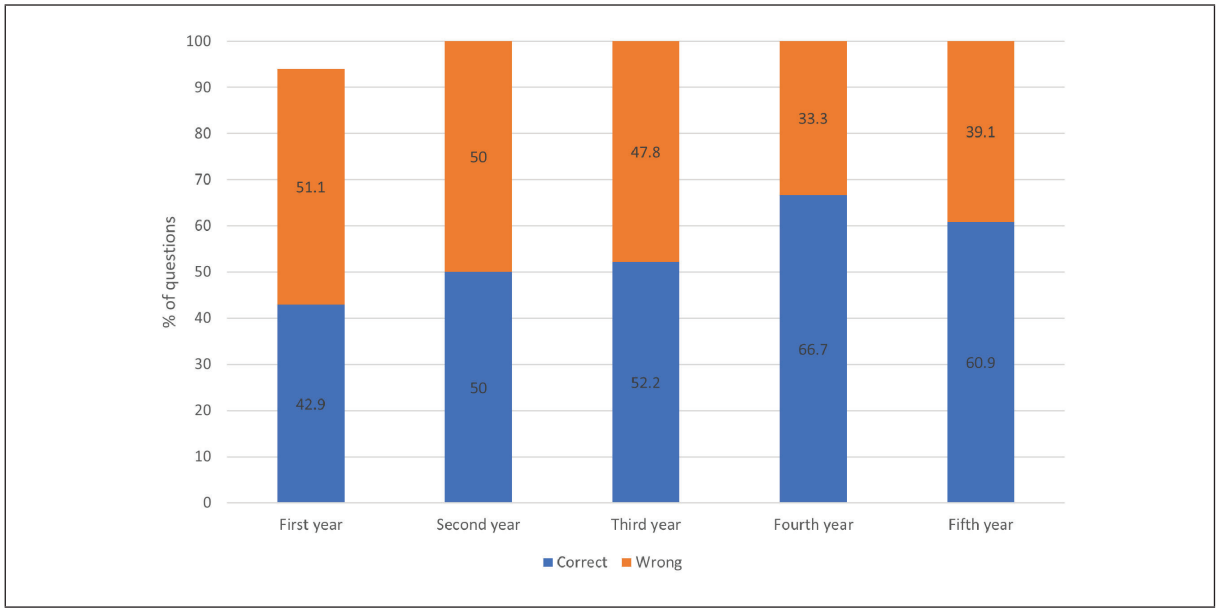

Figure 3
Proportion of correct answers given by the responders.

classes and senior physicians with a dedicated expertise and [12, 14-16]. Moreover, very little attention is paid to ethical reflection and teamwork skills acquisition [17]. On these bases, a mandatory PPC educational program has been proposed for all medical students [18, 19], and accordingly, standardized training protocols are increasingly being offered in some countries [20-24]. These programs include training in specific issues, such as communication skills and managing EOL symptoms, and are based on unconventional teaching methods (e.g. bedside training, "train-the-trainer" model, discussion-based seminar, role play) [23, 24]. Remarkably, in our survey, these approaches have been identified as those potentially most effective, and we therefore feel that the definition of standardized PPC training protocols based on those methods may be considered by relevant bodies. Moreover, the presence of a PPC service can improve not only the management of a child with a LL illness, but also residents' training, in line with previous evidence [25].

CONCLUSION

In Italy, the access to PPC for children with LL illnesses is still limited and many barriers limit development of an adequate network of CPC services. Among these, one of the greatest critical issue is the lack of healthcare workers who are trained in CPC.

Data collected by our surveys suggest that although PPC is well-recognized as primary competencies in a pediatrician's training a poor attention is actually paid to these skills. Therefore, it appears necessary to develop curricula for medical students and design tailored programs addressed to pediatric residents and aimed to the acquisition of knowledge and skills about the management of children with LL illnesses and their families, including also communication methods and principles of bioethics.

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Authors' contribution

Study design: FB, CG, SG; data analysis: CG, LG; data interpretation: all; manuscript drafting: CG, SG, LG; manuscript revision: all; approval to submit: all.

Conflict of interest statement

The authors have no conflicts of interest directly relevant to this study.

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