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Barriers to the development of pediatric palliative care in Italy

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Abstract

Introduction. In recent years the emergence of new types of patient, clinical situations, technological frontiers and "health" objectives have changed considerably the needs of ill children, this also concerns pediatric palliative care (PPC). In Italy, despite the introduction of legislation (Law 38/2010) stipulating the right of children and families to access appropriate services for pain control and pediatric palliative care, the availability of these services is still limited.

Aim. The aim of this study is to highlight, through a review of the existing data and published literature, the critical issues that obstacle the planning and development of PPC services in Italy.

Results. Four main areas identified were: socio-cultural setting; types of patients and nature of diseases requiring PPC; training for PPC providers; regulatory and political issues.

Conclusions. This type of analysis can provide the rational for advancing proposals and developing supportive, corrective and implementation strategies.

Key words

- pediatric palliative care
- organization model
- education
- law
- culture

INTRODUCTION

In recent years the emergence of new types of patient, clinical situations, technological frontiers and "health" objectives have changed considerably the needs of ill children, this also concerns pediatric palliative care (PPC).

Notwithstanding the approval in 2010 of a special law, Italy is sadly behind in the full implementation of PPC. The mentioned legislation (Law 38/2010) [1] strongly affirms the right of children and families to access appropriate services for pain control and pediatric palliative care but, in accordance with the Italian political system, the responsibility for the implementation of these services is delegated to each single Regional Government. The response of the different Regions to this mandate has been extremely heterogeneous and generally ineffective: as a result, only a minority of children eligible for PPC find a response to their needs.

Even the term "palliative" may raise critical concerns [2]: in the Italian language this adjective carries negative connotations of patient abandonment, whereas it is well known that palliative care does not mean to give up, but instead it is a proactive approach [3] aimed at reducing patients' suffering and improving their quality of life. Since it was first used more than 30 years ago, the very expression "palliative care" has undergone important changes concerning its definition, delivery, setting and goals, but these changes have not been accompanied by appropriate modifications of the related terminology [4].

The purpose of this study is to highlight, through a review of the existing data and published literature, the critical issues that obstacle the planning and development of PPC services in Italy.

This type of analysis should provide the necessary grounds for advancing proposals and developing supportive, corrective and implementation strategies relating to the provision of PPC services.

WORKING METHODS

This study was conducted in the form of a critical review of the available literature with the aim of identify-

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ing the crucial issues that interfere with the development of PPC in Italy.

The search in the databases was based on the following terms:

- MeSH terms: pediatric palliative care, life-limiting and life-threatening, end of life, ethical decision, children's death;
- other terms: adolescents, age, barrier, children, culture, family, education, Law 38/2010, organization model, needs, nurse, neonates, parents, patient management, pediatric, pediatrician, psychologist, risk factors, score, variables.

An advanced search strategy was adopted using Boolean operators (and, or, not). Search strategies were obtained by cross-checking the MeSH terms and free terms with the Boolean operators in order to select articles that were pertinent and meaningful for the purposes of our investigation. The literature search was conducted in the following databases:

- primary literature databases: PubMed, Medline, Cinahl;
- secondary literature databases: Trip Database, Cochrane Library;
- Google Scholar, Google Trend;
- the websites of the Italian Ministry of Public Health and of the Regional Authorities.

The articles and other material retrieved were then sorted, and only those dealing with crucial issues and barriers to the development of PPC were examined.

RESULTS

Four macro areas were identified:

- socio-cultural setting;
- types of patients and nature of diseases requiring PPC;
- training for PPC providers;
- regulatory and political issues.

The most relevant crucial issues in each macro area were identified and are described below.

Crucial issues related to the socio-cultural setting

Cultural difficulties encountered when considering death as a possible, and sometimes unavoidable, outcome in the pediatric setting.

The available literature continues to confirm an increase in the prevalence of children with incurable diseases and/or severe disabilities. Advances in medicine and technology have reduced the neonatal and pediatric mortality rates, but they have concomitantly extended the survival of pediatric patients with chronic, severe, and sometimes lethal, diseases [5-7].

Although this situation is well described, there is still a limited awareness of what incurability means as a real problem in everyday life: incurability and death are perceived as situations that only affect adults and mainly elderly persons [8-10]. Children are generally perceived as people just starting out in life, in good health and with long-term survival prospects [11]. There are cultural and emotional reasons, but also misinformation underlying the persistence of such assumptions that are embodied in a – sometimes – unconscious denial of the problem. This can trigger avoidance reactions in the attempt to escape the reality of incurability and death in children; impeding the adoption of interventions aimed at addressing the related needs, changing attitudes and finding solutions, including PPC services [12, 13].

Modern medicine is expected to always provide a cure, and death is perceived as the outcome of treatment failure or human error

There is a widely held flawed conviction that the sole purpose of medicine is to provide a cure through a process of diagnosis, surgery and/or other treatments, even for incurable conditions. The concept of "health" is related exclusively to the absence of disease.

The World Health Organization (WHO) proposes a different, much broader and far-reaching concept of health defining it as a state of psychological, physical and social well-being; it is this state of "health" that modern medicine should strive to promote (http://who.int/about/mission/en/) [14]. This means accepting that medicine cannot always heal everybody, and should not limit itself to controlling symptoms and/or restoring functionality to an organ or system, forgetting that symptoms, organs and systems represent only one aspect of being a "physical, psychological and social person". In this holistic view, it is important to shift the focus to the concept of limit in medicine because "doing everything technically possible" does not always improve the patient's health. Sometimes not doing is better than doing, although doing is often better accepted than not doing. Very often physicians are urged by the families of neonates, children and adolescents with incurable diseases to do everything in their power and an unfounded faith in treatments, or unrealistic expectations of scientific progress lead to refuse the existence of a limit [15-21].

The social difficulty of acknowledging that children have a role as individuals capable of participating (depending on their age and situation) in decisions concerning their health

Pediatric care in Italy has always been a focus of governmental bodies: it is the only country that guarantees not only a family General Practitioner but also a Family Pediatrician free of charge. This has resulted in a persistent fall in neonatal, infant and pediatric mortality rates, placing Italy among the top countries in the world and below the European average, although a difference still persists between the northern/central and southern regions [22].

In Italian society children are generally protected and well cared for, however, adults have some difficulty in perceiving them as "individuals" who (depending on age and capability) should be informed about their illness and involved in care decisions [13].

Communication and patient involvement are fundamental aspects of PPC, and failure to acknowledge this "corollary", or a reluctance to use certain tools, can restrict and sometimes even cancel the opportunities for effective, age-appropriate PPC measures suited to the patient's situation and perception of illness [8-11].

Shortage of information and its inadequate diffusion

Information regarding PPC provision circulated in Italy is grossly insufficient. A multimedia-based as-

sessment of the interest in "PPC problems" using the Google Trend search engine demonstrated that the issue attracted more attention at a national level during the month of March 2010, when Law 38/10 was approved. Since then there has been a constant decline in relevant studies and general interest in the problem [23], despite important initiatives and publications on PPC (also by Italian authors) in the last five or six years. Among them, it is worth mentioning two documents that had important and immediate social effects, but that have been granted very little space in the media. One is the "Trieste Charter" completed in 2013, which establishes the ten inalienable rights of the dying child [24]. The other is the "Religions of the World Charter for Children's Palliative Care", the goal of which is to acknowledge, through the voice of the principal world religions, the importance of PPC as the most appropriate solution for helping children with serious illness to achieve the best possible quality of life, protecting their own and their family's dignity [25, 26].

The shortage of information on these issues probably responds partly to a market-driven logic. It is rather difficult and sometimes counter-productive to deal seriously and objectively with such complex subjects such as disability, incurability and death in childhood. The outcome of evading the issue is that very few people understand and discuss this aspect of medicine, and, as a consequence, it may limit the demand for/or acceptance of PPC, even when it is available.

Limited understanding of pediatric palliative care

Published studies have shown that the Italian population's understanding of PPC is often erroneous or incomplete [27, 28]. It has been estimated that around one in two Italians have never heard of palliative care, only 23% have an adequate or precise idea of what the term means, and 27% have heard of palliative care but do not know what it involves or have misconceptions about it. A commonly held opinion among care givers is that PPC only relates to the terminal stage of the disease, and that children up to seven years old have no need for PPC, irrespective of their condition [29]. Nationwide, there is a very limited awareness of the legislation governing access to palliative care; only 15% of Italians know about the Law 38/10 and of the rights deriving from it [28]. This situation severely limits and sometimes even prevents the activation of PPC services.

Crucial issues related to the type of patients and nature of diseases requiring PPC

The peculiar characteristics of pediatric patients

Neonates, children, and adolescents are very special patients, particularly regarding their diagnosis and potential treatment [13]. Pediatric patients are developing physically, emotionally and cognitively; this fact influences all aspect of their care: recording their medical history; conducting medical examinations, planning a diagnostic work-up, administering treatments, the choice of drugs, communication, and relationships [13]. Their special patient status also involves the related ethical, normative and social aspects. When a patient is a child, the idea of shared decision-making and autonomy becomes complicated and needs to be modulated according to the patient's age, cognitive level and relational abilities, as well as to the clinical situation. From a normative standpoint, the reference persons are the parents or other adults with parental authority, and the care team must discuss any decisions and treatment options with them. This is an extremely complex area where ethics and legislation may differ substantially.

Numerous experiences have shown that the majority of children with serious illness are aware of their condition, and demonstrate a remarkable maturity and capacity for understanding [30]. Starting from school age, children are capable of grasping the severity of their condition and the meaning of death [12], but in our professional experience their participation in decisions concerning their health is still limited in our social and public health settings.

Type of disease

Unlike adults, the main cause of incurability in children is not oncological [30, 31]. Approximately only 20% of children eligible for PPC suffer from neoplastic diseases, while the other 80% may have a variety of other, often rare conditions, that are mainly neurological, neurodegenerative, metabolic, genetic/chromosomal [12]. Therefore, they constitute a very complex patient population to care for, and the course of their disease and their life expectancy, though always limited in time, can be variable and often difficult to predict [32]. Caring for such children requires not only highly-specialized clinical expertise, but also an equally indispensable competence and knowledge in the organizational, communicative, relational and ethical spheres [32].

Patient numbers

The number of pediatric patients with incurable illness eligible for PPC is far lower than that of the adult or elderly populations with PC needs [28]. Nonetheless, several national and international studies have shown that at least 10/10 000 minors (aged 0-18 years) are eligible for PPC [5, 6, 33]. Their number has risen continuously in recent years and some authors claim that presently it is almost 30/10 000. It has been estimated that at least 11 000 minors (aged 0 to 17 years) become eligible for PPC in Italy every year. This figure is probably a gross underestimation since, according to the latest studies, it could realistically exceed 30 000 children [5, 34].

This relatively small number of patients needing PPC (by comparison with adult patients), associated with the heterogeneity of their clinical condition and their widespread geographical distribution, creates numerous organizational problems and difficulties in the provision of information, staff training and the implementation of appropriate, dedicated services.

Role of parents and families

A diagnosis of incurable illness in a child has a dramatic impact on families, severely impairing their quality of life [35-38]. One of the greatest difficulties encountered when caring for these children consists in how to address the family's suffering and burden of care [12].

Parents often experience contrasting feelings: impotence, frustration, fear and anxiety can interfere with their decision-making capacity. Recent studies suggest that the driving factor behind the parents' care-choices for their children lies in their determination not to give up [39]. Within this context, the inability to accept a diagnosis of incurability and the conviction that referral for PPC is equivalent to giving up any chance of cure represent the most critical issues [40]. Honest and exhaustive communication is fundamental to help parents accept the child's prognosis and prepare them for their child's present and future needs [41].

Shortcomings in training for PPC providers

The healthcare staff curricula do not include training in PPC

The delivery of appropriate PPC relies on the availability of healthcare workers with specific knowledge and expertise in providing this type of care [31, 42, 43]. In Italy, training of healthcare professionals in PPC is incomplete and inadequate thus representing an important barrier to the full implementation of Law 38, since it does not guarantee a qualified and equitable response to the need for PPC all over the country.

In 2000, the American Academy of Pediatrics recommended an adequate training in PPC for all pediatricians to ensure that they are able to activate the necessary procedures competently [44]. Numerous studies have recently examined the training that physicians receive regarding PPC [45-52], and the quality of services offered [53, 54]. The professionals' knowledge was found inadequate, and the barriers to the implementation of PPC considerable [15, 17, 27, 40, 55]. In Italy, only 50% of physicians specializing in pediatrics receive any training in PPC during their 5-year course of specialization – and even when they do so, it is very bland indeed, involving a commitment to study/training averaging no more than 60 minutes a year [56].

Also in the nursing sector there is currently no specific training provided in PPC. A modification to Article 31 of Directive 2005/36/EC, contained in Directive 2013/55/EC, and now incorporated in a publication by the European Federation of Nurses Associations, calls for the inclusion of training in "pain management, palliative and end of life care" among the compulsory topics of nurse training [57]. The Member States' commitment to implement these directives expired on the 18th of January 2016, but has yet to be become effective in Italy.

It is evident that the lack of staff training is one of the most critical obstacles to PPC provision and that dedicated training in PPC should become an integral part of the curricula of the diverse professional figures involved in pediatric care [15, 17, 52, 58]. In Italy, training curricula for this purpose are available and the specific core competences established [43, 59]. However, the organization of training initiatives according to the mentioned curricula is still in a very early phase.

Limited awareness of healthcare professionals and others in the problem of PPC

In 2016, six years after Law 38/10 was approved, a study was conducted to assess the awareness among Italian pediatricians' about PPC. Less than half of the physicians contacted responded and, among those who did, 82% knew little or nothing about the provisions of the Law; 50% of pediatricians were not aware whether there was a reference center for pain management and PPC in the area they covered, and 84% felt they lacked the knowledge and competence to provide PPC [60].

The poor response from public healthcare staff and other professionals to surveys investigating their awareness of PC and PPC has been confirmed by several other published studies [52, 56, 58, 60, 61].

This picture is in stark contrast with the increasing attention paid to this subject in the scientific literature: 40% of the articles about PPC available on PubMed (4683 contributions) have been published in the last decade and appear in the programs and other documents released by international organizations, institutions, and governmental bodies (including the United Nations and the World Health Organization) (Cure palliative pediatriche: l'Onu chiede di adottare la legge italiana 38/2010 come "model law". Available from: http://www.federsanita.it/html/notizie/it/Cure-palliative-pediatriche-Onu-chiede-di-adottare-la-legge-italiana-38-2010-come-model-law.asp).

Complexity of the competences needed for PPC provision and shortcomings in healthcare professional training

In addition to the knowledge and clinical expertise relating to the specificities of their role, each member of a PPC team must have other abilities, these include: organizational, communicational, relational skills and a strong team spirit; they must also be proficient in ethical problems [15, 43, 48, 50, 62-66].

Numerous studies have shown that the main barriers to the development of PPC include inadequate training in communication and how to work as part of a team. These shortcomings can negatively impact communication in different circumstances: between physicians and the patients' parents/family, between professionals with different roles and specializations, between the members of the PPC team, and even between patients and their families [16, 61, 67, 68].

The lack of adequately trained staff is responsible for limited or ineffectual response to the problems of incurable or dying children, and it reduces the credibility and/or impoverishes the value of PPC.

Crucial issues related to regulatory and political aspects

The Regional Authorities' different schedules for implementing the legislation

There is a considerable body of legislation relevant to PPC in Italy [1, 69, 70]. As already mentioned, Law 38/2010 identifies the Regional and Autonomous Provincial Authorities as the parties responsible for presiding over the implementation of PPC networks through the identification of experts and the accreditation of patient care facilities in their territory [1]. While granting ample freedom for the territorial organization of these services, this model has impaired a standardized nationwide adoption of the legal provisions. According to the report of the Special Office of the Ministry of Health, at

present, only a few of the 22 Regional Authorities have developed a PPC network. These are active in five regions and, in various stages of development, in another four [28]. Local political and cultural factors probably also condition, to some degree, in the methods and types of response adopted [71].

Economic problems

PPC services represent a new, dynamic and complex area of patient care, requiring dedicated resources (especially during the set-up phase) which are not always available or forthcoming. However, there is consensus in literature that PPC networks, not only improve the quality of patient care and the quality of life for patients and their families, but they may also achieve significant economic savings [72]. The initial financial commitment is unavoidable, however, refusing to take a long-term view, focusing primarily on the first stage of implementation of PPC networks, has probably restricted the commitment to their planning and their practical application. Analyzing the costs of complex networking models recommended for PPC services is by no means easy, partly because there are insufficient standardized data available for comparisons, and partly because it is essential to consider not only the costs for the public healthcare system, but also the multiple and diverse social costs, which are difficult to quantify and standardize.

Organizational problems

There are few reports of experiences of PPC networks in literature, and only a limited number of organizational models have been studied. Among them a network serving a macro area represents the reference model, which takes into consideration the heterogeneous nature of the situations involved and the different types of patient care needed [1, 7, 12, 30, 69].

Such a network includes all the staff/services needed to take care of the patients and their families. An inadequate understanding or misconception of PPC at various decision-making, management and operational levels negatively influences how the whole public healthcare system is organized in an area and severely restricts the chances of a network being set up and managed effectively.

DISCUSSION AND CONCLUSIONS

This study was aimed at the identification of the most critical barriers for the implementation of PPC in Italy. It has become evident that many of those barriers are strictly related to the political, social, cultural, traditional, legislative, geographical and organizational characteristics of the country. Other countries may be faced with similar or different difficulties depending on their specific social, political and health care organization.

For this reason a comparison between the Italian situation and that of other countries has not been considered in our study.

Numerous crucial issues and barriers have been identified. Some, like the political and cultural issues, are difficult to modulate and modify, while others are easier to influence and overcome, such as the shortage of appropriate training programs for healthcare professionals [72].

All these issues and barriers necessitate a change of approach: the problem of PPC needs to be acknowledged socially, professionally and at planning level, and be recognized as an indispensable service for incurable pediatric patients.

Our analysis is a first step in that direction since it provides the necessary basis for formulating proposals and establishing strategies for implementing, supporting, correcting PPC services in Italy.

Conflicts of interest statement

None declared.

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