

Health professionals' perception of appropriateness of care: a qualitative study in Italian pediatric hospices

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Summary. *Background:* Appropriateness is particularly relevant in palliative care, an area in which it is essential to question the real need for treatments. Few studies explored the perception of appropriateness by professionals in pediatric palliative care, revealing the conflict sometimes faced when confronted with the uncertainty of prognosis and end-of-life decisions. *Aims:* The objective of this study is firstly to investigate the perception that doctors, nurses and psychologists, operating in Italian pediatric hospices, have of the appropriateness of the care they provide. Secondly, to understand what repercussions the perception of non-appropriateness has at individual and team level. *Methods:* A qualitative study was conducted between 2019 and 2020 through semi-structured interviews with a convenience sample of 17 professionals working in Italian pediatric hospices. *Results:* The interviewees do not refer to a common concept of appropriateness, but compare the latter to: the quality of life, the global care of the assisted person, the proportionality of care, the early recognition of the need for palliative care. The discussion within the team emerges as a privileged place to manage the discomfort of individual professionals in the face of treatment choices in conflict with their own values. *Conclusion:* the non-referring to a univocal conception of appropriateness deprives professionals of an objective criterion to resolve the most difficult decisions. However, it allows them to establish what from time to time seems to be the most appropriate care pathway for a given patient, at a given time and context, preserving the goal of personalized care. (www.actabiomedica.it)

Keywords: Appropriateness; Perceptions; Health Professionals; Palliative Care; Pediatric Hospice; Italy; Qualitative study; Interviews

Introduction

Exploring the theme of appropriateness requires dealing with a complex and multidimensional concept, which has undergone and will continue to undergo several changes over time. Considering the etymology of the word, something is defined as appropriate that is “suitable, convenient, right” in the context or

situation in which it occurs. The Zingarelli dictionary (2020) of the Italian language defines with this term what «fits perfectly to a given circumstance or that responds precisely to a need». It is clear, therefore, how the concept of appropriateness has the characteristics of conventionality, that is, it must always refer to the socio-cultural context, to the historical moment (including the stage of development of medical science

and technology) and to the system of values at the within which its perimeter is established from time to time. In the health field, appropriateness is expressed within a cost-effectiveness relationship, and understood as the result of a decision-making process that ensures the maximum net benefit for the patient's health, within the resources that society makes available (1, 2).

The principle of appropriateness of care is strictly connected to the sphere of Palliative Care (PC) and to that of assistance at the end of life, since it is inherent in the philosophy of the PC to question the real need for treatment and the benefit that is given to the person not in terms of healing but rather of care (3-6). Similar attention is the one that moves the work of professionals working in the field of Pediatric Palliative Care (PPC), who today find themselves managing, for long periods of assistance, some pathologies that until recently would have guaranteed the child a short-term poor prognosis (7).

The process that guides the definition of appropriateness of care in PPC involves different areas: clinical, legal and administrative, economic, interpersonal (between patients, health professionals and caregivers), intra and interprofessional. Furthermore, it involuntarily calls into question the personal judgments and opinions of those who find themselves confronted with criteria of appropriateness that are often not self-evident. The complexity of taking charge in PPC is not given only by the type of patient and the identification of his/her and his/her family's needs; it is amplified by the presence of numerous and different "actors" involved in the care project (intensivists, pediatricians of free choice, PPC team, child, family, etc.), who can be carriers of different perceptions of appropriateness. All this can lead to conflict situations, between professionals and caregivers, or within the same multi-professional team, which occur more often when the weight of the decisions to be made is particularly burdensome and, in particular, when these decisions concern the end of life (8).

Background

A literature review published in 2008 (9), referring to an observation period between 1966 and 2006,

found that the concept of appropriateness, in the studies examined, was defined above all in reference to the positive effects for the patient.

Even the definition that still today, at an international level, is most commonly used to define the term "appropriateness", starts from the declination of these effects. This definition was developed by the American organization RAND Corporation and defines a procedure as appropriate when the expected benefit (e.g. increase in life expectancy or pain relief) outweighs the expected negative consequences (such as anxiety and pain) by a sufficiently large margin to make it considered worthwhile (10). Accordingly, a procedure which risk is higher than the expected benefits is therefore considered inappropriate. The limits of this definition are attributed to the lack of taking into account the individuality of the patient and the availability of resources for health care, two issues that since the 1990s have also entered Italy in the debate on the quality of care and its sustainability for the system as a whole. The concept continues to remain difficult to clarify, so that a review of the evidence available to define appropriateness concluded that the judgment on it «depends on the doctors to whom the question is addressed, on the place where they live and work, on the weight attributed to the different types of evidence and end-points investigated, on the fact that the preferences of patients and families become part or not of the reasoning, on the amount of resources in a given health system and finally on the values prevalent both in the system itself and in the society in which it developed» (11).

In Italy, in the Legislative Decree 229/1999 and the subsequent Prime Ministerial Decree of 12 January 2017, appropriateness is recognized as one of the principles to be respected by the National Health Service in guaranteeing the Essential Levels of Care (LEA) and as a criterion on which basis the inclusion/exclusion in the LEA of certain types of assistance, services and health services can be assessed. However, it is equally complex to identify a definition of appropriateness in legislative and programming documents. It is certain that, within them, appropriateness is identified as a dimension of the quality of care which «should be provided respecting the patient's clinical picture and the indications for which it has proved effective, at the right time and according to the most

appropriate organizational regime. The variables to be considered go beyond the patient's specific clinical features, including, for example, dimensions such as quality of life. Furthermore, the consideration of the cultural and organizational context of both the patient and the operators and the framework of compatibility *hic et nunc* are always part of the definition of appropriateness» (3).

The appropriateness of care is closely connected with the area of Palliative Care and assistance at the end of life with respect to the criteria that define the proportionality and non-proportionality of care, "therapeutic obstinacy", suspension of care and respect for the person's will. The fact that health systems must equip themselves with criteria that define the appropriateness of care, and that health professionals are required to respect them, must be reconciled with the fact that decisions at the end of life, especially in a pediatric context, often meet difficulties related to the treatment path not shared by family members and the non-acceptance of the death of their child. With regard to taking care of a child in the terminal phase, research reports that it is desirable, in fact, that each family, together with the clinical team that supports it, find solutions that are as personal as possible, based on their own resources and values, cultural beliefs, spiritual and philosophical and that professionals must accompany the family to understand the situation and the possible choices in terms of potential benefit and harm (6). All this is further complicated by the fact that the spectrum of pathologies potentially eligible for PPC appears heterogeneous and broad, as well as the spectrum of needs that the illnesses themselves trigger and the very duration of palliative care in children with incurable disease appears to be a very variable parameter and difficult to predict (7).

The debate on appropriateness in PPC found in the literature is felt above all in reference to the setting of pediatric and neonatal intensive care, since in this context, end-of-life choices are a great challenge for operators (12). Healthcare professionals in pediatric intensive care experience greater moral distress if they perceive therapeutic persistence towards a patient rather than facing the option of not treating the patient (13). There are few studies that examine the topic of the perception of the appropriateness of care by PPC professionals. Some of these (8, 14-16) by noting

the perceived obstacles of health professionals in proposing PPC, highlight the conflict which is sometimes created among professionals when faced with the uncertainty of prognosis and decisions about the end of life. The need that is reported in almost all of these studies is the need for personnel with specific training on PPC, as well as notions of bioethics, in order to guarantee adequate assistance to the family, especially in the moment of difficult decisions (13, 17, 18).

Aims

The primary objective of this study is to investigate the perception that professionals (doctors, nurses and psychologists) who work in PPC centers and Italian pediatric hospices have of the appropriateness of the care provided to minors in the same centers. The secondary objective is to understand what possible repercussions the perception of inappropriate care has on the individual operator and the team, and whether this experience has any effects in daily clinical practice.

Methods

An explorative study, that adopts a qualitative research strategy, was built around the collection of semi-structured interviews with a convenience sample of professionals (doctors, nurses, psychologists) in service at all the centers classified as pediatric hospices on the Italian territory. Participants included in the study are health professionals serving in five PPC services, regardless of age or length of service, recruited based on their work setting, professional role and willingness to participate.

The interview outline was built around three macro-areas of investigation relevant to the research objectives: criteria for eligibility and admission to PPC, daily clinical practice, experience/lived situations of operators with respect to the appropriateness of care.

The interviews were carried out between November and December 2019, at the place of work of the interviewees, and lasted between 13 and 53 minutes. Conducted individually by five different members of the research team, after specific training, only one

interview saw the presence of another member of the group in the role of observer.

Before the start of the interview, the interviewees were asked to sign a consent form for participation in the study, a form on the protection of privacy and the processing of personal data (anonymously) and a consent form for audio -registration of the interview.

The collected interviews were audio-recorded, then literally de-recorded and thematically analyzed, by each researcher separately.

For the analysis of the data, the main thematic areas that emerged from the interviews carried out were identified collectively. Subsequently, each member of the research group re-analyzed each interview by coding a particular thematic area among those previously identified. In this way, the point of view of all the researchers on all the interviews was maintained, limiting the risks due to the partiality of a single interpretation.

Only the professional role of the participants was made recognizable by using the following letters: “N” for Nurse; “P” for Psychologist, “D” for Doctor, followed by a single, progressive number for each participant which was assigned during the anonymization phase of the interviews.

Results

Seventeen professionals were interviewed: 5 psychologists (of which 4 females and 1 male), 6 doctors (of which 5 males and 1 female) and 6 nurses (all females). In four out of five hospices it was possible to interview at least one professional per category. Only in one of the facilities two doctors and a nurse participated and it was not possible to interview a psychologist.

The thematic macro-areas identified in the analysis phase of the interviews concern the following aspects, raised by the interviewees with reference to the topic of appropriateness, which will be further explored below:

- individual conception of appropriateness;
- eligibility criteria and borderline cases;
- team work;

- relations with the minor and caregivers;
- situations of personal disagreement/discomfort of professionals;
- training of professionals on the topic of appropriateness.

Individual conception of appropriateness

In order to explore individual conceptions of appropriateness, during the interview, we asked the participants an intentionally broad question: “If we talk about appropriateness of care, what comes to your mind?”. From the analysis of the interviews, it is difficult to find a common or unique definition of appropriateness. The interviewees, in fact, declined the concept with reference to some practices, procedures or objectives characterizing the setting of pediatric palliative care:

- early recognition of eligibility for palliative care;
- the overall care of the patient and his family;
- the response to the identified need;
- the quality of life;
- the proportionality of care;
- personalization of care;
- “knowing how to stay”.

With respect to eligibility for pediatric palliative care, doctors, in particular, understand appropriateness as a non-fully achieved standard, highlighting the gaps in the early recognition and reporting of the need for palliative care in pediatric patients. On the other hand, there are no emerging differences, within the three professional categories, with respect to the consideration that a treatment path can be defined as appropriate when it provides for the overall care of the minor (and his/her family): “*In my opinion it tends to be linked to the aspect of the need and the global taking in charge, that is a cure is appropriate where, in such a context, the patient’s needs are understood*” (P-1).

The adequate response to a patient’s need is another recurring declination of the concept of appropriateness: “*a care that is dedicated and that is prepared to be able to approach what is the theme that is requested*” (P-11); “*... appropriate because it resolves or in any case addresses the problem raised, the patient’s problem*” (D-2).

A lower number of professionals, on the other hand, connect the concept of appropriateness to safeguarding the quality of life: *“Working in palliative care, appropriateness for me generally means doing everything that is necessary for the person so that he/she can experience a quality of life that is as dignified as possible up to the end. For me, appropriateness means being able to share, in this case with the parents, when it is appropriate to start removing everything that is too much and everything that is ineffective and that does not provide a benefit for the child”* (P-14). Referring also to the wishes of the family, not only of the patient, some professionals reconnect the concept of appropriateness to another significant theme in the field of Palliative Care, namely the proportionality of care: *“with appropriateness it comes to mind that care is proportional to the objectives we want to achieve”*(P-6); *“appropriateness reminds me of hospitalization, therapy or assistance appropriate to the condition, situation in which the patient is at that moment”* (N-9); *“... in the path of shared planning of care with patients and with the family and that therefore [appropriateness] also has to do with proportion, with proportionality”* (D-13).

Finally, appropriateness is recognizable in the affirmation of the centrality of the individual in the choices of care: *“For me, appropriateness of care simply means sewing a tailored suit: the patient is unique and unrepeatable, we have no manual, no fixed method for that determined... replicable, we cut the assistance to measure to the patient”* (N-3); *“We adjust therapy or assistance, care for the child without considering the disease but the child”* (N-8).

The last theme associated with the concept of appropriateness is that of “knowing how to stay”, which emerges as the *“ability to be able to stay in what is the situation that is required, therefore in one’s role with one’s own limits, with one’s professional skills, naturally”* (P-11).

Only with respect to three declinations of the theme of appropriateness is it possible to detect a common perception within the professional category:

- psychologists have more often expressed the concept of appropriateness in relation to the quality of life;
- doctors raised the issue of delayed referral of patients to the attention of pediatric palliative care;

- nurses focused attention on personalizing the care.

Eligibility criteria

A certain heterogeneity emerges from the analysis of the interviews regarding the criteria used by hospices to evaluate the appropriateness of hospitalization requests. Among the most cited modalities, the ACCAPED score, the PaPaS scale, but above all the discussion of the case in the team appear: *“we often confront each other as a team ... the patient’s incurability is fundamental, then if the Accaped scale gives an adequate number, this means that in any case the patient has such needs”* (D-7); *“... we do not have real guidelines, we discuss them together”* (N-3); *“Simply evaluating with colleagues who report it to us and then taking note of any elements that may actually justify or require hospitalization in hospice. More than guidelines, criteria essentially linked to disability”* (D-10).

As for the limitations with respect to reception in terms of age, residence or pathology, age would seem to be the most used criterion since pediatric palliative care must be aimed at an age group up to 18 years. However, in clinical practice, it emerged that this limit is not binding for hospitalization: *“There are the restrictions established by the Region (...). After which the policy is to take everything [smiles] even without accreditation, but this is because it is a philosophy that our structure has always had”* (P-14).

Most of the interviewees, with respect to the issue of welcoming borderline cases, report that the discussion of the case in a team is the most used approach to make decisions even when there are conflicting opinions. Someone points out that *“we compare ourselves... the comparison, however, does not mean that the team decides. That is, the decision on admission is always a decision to be taken by the doctor, nursing coordinator and the social worker”* (P-14).

Teamwork

A fundamental element of pediatric palliative care assistance is team work. Even with respect to the theme of appropriateness, the comparison in a team is perceived as essential to harmonize any differences

of views: “... it is always useful because it helps in any case to clarify the level at which you can be and adequately recognize yourself with respect to your values, your moral principles but also, to respect your professional skills and therefore also to understand what is the threshold in which you can risk the situation” (P-14); “Teamwork means that we certainly put on the plate our points of view with respect to interventions but also with respect to our disciplines because it is true that they integrate but they are different disciplines, so they are different perspectives” (P-1). Among the strengths of team work, with respect to the discussions related to the theme of appropriateness, there is the fact of arriving at a shared choice, important to keep especially in front of family members: “what we search for is the harmony between what we see and think as a good intervention and what is expected, the expected of the parents, by the patient with respect to a certain type of intervention” (D-2); “... we always try to talk to each other and we all try to reach a unanimous decision” (N-4). A method that some professionals find useful in helping to approach the solution of a discussion on appropriateness is the involvement of the bioethics committee or a bioethicist, because “it is as if this figure gives structure to a thought that is sometimes a thought filled with sentiment” (D-13): “Sometimes we refer to an opinion of the ethics committee, when there is disagreement in the team” (D-7); “... luckily we have the pediatric bioethics committee (...), its president often comes to team meetings with us and this helps us a lot to decide” (P-6); “... we will discuss difficult cases at least two, three times a month and there will be out of these about thirty difficult cases that will put us in a position to have to discuss them as a team, in my opinion ten percent of these cases goes to the ethics committee, the other times we manage to resolve them among ourselves, perhaps also relying on the ethicist” (D-7).

Relationship with minors and caregivers

During the interview we asked the professionals if, during the assistance, it happens that the caregivers or the minor are concerned about the appropriateness of the care proposed by the team and how this can modify the established treatment path. The majority of operators (15 interviewed out of 17) report that caregivers often raise doubts. This would seem to

happen above all when the disease is in an advanced stage and an active approach is no longer adopted (e.g. chemotherapy drugs, antibiotics, etc.) or a palliative one: “they absolutely require that everything should be done. Which is a bit of a contradiction, because some of the drugs are frankly useless; therefore rather than an opposition to a request we have been asked to continue with such treatment” (D-2); “We follow the will of the parents, of course, we also surely provide psychological assistance to see if we need to change this type of attitude over time according to the clinical conditions of the patient” (N-8). Only three operators report perplexity on the part of the minor with respect to the therapies or interventions proposed by the pediatric palliative care team. However, the common thought emerges in the interviews that the will of the child must always be put at the fore and respected.

Changes to the treatment path planned during the child’s care seem to occur very frequently, in particular to satisfy the parents’ requests: common sense, negotiation, mediation, acceptance are some of the most common keywords by the operators interviewed. In a certain sense, the team seems to be prepared for this eventuality, aware of having to facilitate the parental acceptance process.

Situations of professionals’ disagreement/personal discomfort

During the interview, we asked the professionals if they had ever felt in disagreement or in uncomfortable position with their personal opinions and principles, when faced with the application of certain therapeutic treatments. Some of the interviewees report that they never felt in disagreement. Others, on the other hand, claim to have felt profound discomfort. In most of these cases, the choices they disagreed on were made by professionals from teams outside of pediatric palliative care, or by parents. In these cases, the discomfort is expressed by the operator as an emotional state of frustration and a feeling of sadness and loneliness given by the perception of inappropriateness: “I felt very uncomfortable in this situation because I evaluated, in my opinion, that keeping him intubated for seven months it was not the correct solution for the good of the child...” (N-8); “... we do not agree with that team,

that is, it happens to us very often, because they see hopes, therapies, things to do that could extend the life time, but many times they immensely worsen the quality of the life of this child. It is difficult to be close to families when this happens" (P-6); *"... especially on existential/psychological suffering, which I think is also a bit my field, I see that it is greatly underestimated in general"* (P-14); *"Well I've been asked for euthanasia several times. I am against euthanasia, so..."* (D-17).

In general, the professionals declared greater discomfort in moments when they found themselves facing certain situations alone and felt abandoned by the team. However, it would seem that personal disagreement or discomfort did not affect professional action and professionals agree that team communication, discussion with the work group and openness to colleagues are the best ways to try to re-establish the "equilibrium". In some cases, faced with decisions on appropriateness that could conflict with their own personal opinions, they finally relied on the guidance of more experienced people: *"Up to now I have also been guided by those who are more experienced and older than me"* (D-7); *"I communicate my thoughts, I share them here... then from an emotional point of view they are loads that we have... and that is why supervision is essential for us"* (N-16).

Training on appropriateness

All the interviewees, solicited on the subject, agree that training in the field of appropriateness is useful. The declared aim is the desire to find a common method and to have tools available that are as objective as possible: *"... to have tools that allow you to do it in a ... scientific and not subjective way. It is certainly useful both for each individual professional and for the team and the group"* (D-17). An associated issue is the need, identified by some of the interviewees, for ethical/bioethical training that allows understanding *"when to leave and when to stop"* (N-3). The peculiarity that emerges is that many of the interviewees believe that training on appropriateness is necessary especially for those who do not work in the field of pediatric palliative care. This, in their eyes, could favor the early recognition of palliative care needs and the involvement of the palliative physician in care pathways.

Discussion

The concept of "appropriateness of care" is related by the participants in this study to the quality of life of the patient, to the need for early recognition of the need for pediatric palliative care, to global care, to the personalization and proportionality of care and to "knowing how to stay" with the minor and with the family. These aspects can only be partially traced back to the dimensions that, in literature, characterize the complex concept of appropriateness. For example, there is little or no mention of the economic and bureaucratic-legal dimensions, instead reported by Sharpe and Fade (19) and Morosini and Perraro (20) as fundamental elements in order to define a certain treatment as "appropriate". What emerges, however, in clear confirmation of what was observed by Hopkins (21), Zanetti (22) and Vasselli et al (3) is the consideration of appropriateness as a judgment or criterion to be determined in each individual case, with respect to a specific context and at a given historical moment. It is thus, for example, that eligibility for hospitalization in pediatric palliative care is, like some treatment strategies, discussed and renegotiated according to the type and need of the patient, the requests or needs of the family, the path of previous care and other context and time-dependent factors.

This study shows that healthcare professionals working in pediatric palliative care in Italy question the appropriateness of care whenever they take care of a newborn/child/adolescent. While not referring to a common perception of appropriateness of care, the interviewees, in fact, converge in adhering to a definition of appropriateness that defines a service as appropriate when it takes into consideration not only the patient's clinical problems but also the patient's quality of life, meant as physical and mental well-being.

From the interviews, as well as from the literature (14), the need for more defined criteria or protocols emerges to help professionals in the decision-making process regarding the appropriateness of care, especially in more complex cases. Tools such as the ACCAPED and PaPas rating scales are mentioned by some of the participants to attempt to objectively identify patients' needs. However, the most commonly used strategy to help professionals make decisions in borderline cases

appears to be the discussion of cases in a team, possibly even asking the bioethicist for advice.

Several issues emerge from the interviews that are also reflected in the literature. The most evident is the centrality of the multidisciplinary team and the need for it to reach a shared decision on the treatment path to be proposed (23), also to be able to support it in the face of the expectations and requests of the families of minors (15). The disagreement between caregiver and team arises, in fact, in particular, in the terminal phases, when active therapies and interventions are no longer possible and parents are offered a palliative approach to exclusive symptom control. The need for specific training on the appropriateness of care in the field of pediatric palliative care and training in bioethics that emerged from the interviews is also confirmed by several studies published in literature (13, 17, 18, 24, 25).

The participants in this study then confirm the difficulties faced by professionals, found in the previous studies (8, 16), with respect to the sense of frustration and sadness experienced when the decisions made by the team are not in line with their values or moral principles. However, this position of inner disagreement, according to the professionals interviewed, does not seem to affect professional action and the relationship with the caregiver/patient.

Conclusion

The results of this study first bring to light the limited knowledge, on the part of professionals, of the debate not extensive but present in the literature, on the appropriateness of care in pediatric palliative care. The absence of a univocal definition of appropriateness, fixed once and for all, deprives professionals of a shared and objective criterion, for which they feel the need, to settle the most difficult decisions. However, this allows them to establish, through a team discussion, what in science and conscience appears from time to time as the most appropriate treatment path

for a given patient, at a given time and context. Precisely because of the variety of situations to which the interviewees attribute salience with respect to the issue of appropriateness of care, this research has made it possible to shed light on some critical issues of daily clinical practice in pediatric palliative care, which it is hoped that future research will help address. Finally, having detected cases of suffering on the part of healthcare professionals in the face of decisions in conflict with their personal values could bring to the attention of the Health Authorities and Hospices the need to increase the opportunities for training and internal supervision to reduce, if not prevent, possible burnout situations resulting from the feeling of emotional discomfort.

The study limitations mainly concern the exploratory research method and the convenience sample adopted: the findings can concern only the contexts and the professionals involved, even if the recruited professionals belong to different Italian realities and regions. Further research would also benefit from a deeper exploration of the existing literature, which in this fieldwork research has been examined mainly by way of scope.

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