Title:

Ethical dimensions of Paediatric Nursing: A Rapid Evidence Assessment

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Abstract

Background: Paediatric nurses often face complex situations requiring decisions that can be in

conflict with their own values and beliefs, or with the needs of children and their families. Paediatric

nurses often use new technology that changes the way they provide care to children, but this may

generate ethical issues, and which nurses should be able to identify, understand, and manage in the

full respect of the child.

Research question and objectives: The purpose of this review is to describe the main ethical

dimensions of paediatric nursing. Our research question was: "What are the most common ethical

dimensions related to paediatric nursing?"

Research design: A Rapid Evidence Assessment

Method: According to the principles of the Rapid Evidence Assessment, we searched the PubMed,

SCOPUS, and CINAHL databases for papers published between January 2001 and March 2015.

These papers were then independently read and analysed according to the inclusion criteria.

Ethical considerations: Since this was a Rapid Evidence Assessment, no approval from the ethics

committee was required.

Findings: A total of ten papers met our inclusion criteria. Ethical issues in paediatric nursing were grouped into three areas: a) Ethically difficult healthcare situations; b) decision making problems; and c) Social responsibility.

Conclusions: Only few studies investigate the ethical dimension and aspects of paediatric nursing, and they are mainly qualitative studies conducted in critical care settings based on nurses' perceptions and experiences. Paediatric nurses require specific educational interventions to help them resolve ethical issues, contribute to the decision making process, and fulfil their role as advocates of a vulnerable population, such as sick children and their families. Further research is needed to investigate how paediatric nurses can improve the involvement of children and their families in decision making processes related to their own care plan.

Keywords

Ethical dimensions, ethical issues, ethical competences, paediatric nursing, responsibility

Introduction

In the last few years, there has been a growing interest on behalf of healthcare organizations in nurses' ethical competences because there is evidence that they play an increasingly important role in biomedical sciences, due to changes in the way health care is provided, scarce resources, and conflicting values. Ethical competence is an intrinsic element of nurses' professional responsibility and difficult situations are increasingly common in nurses' daily practice, and often require them to make decisions that are in conflict with their own ethical or moral beliefs [1, 2].

In paediatrics, when children are unable to cooperate, for health professionals it is difficult to make decisions that have implications for their life and death, and such situations often lead to ethical issues and disagreements about treatment, procedures to adopt, and health care choices [3, 4, 5, 6]. Moreover, the field of paediatric care is characterized by rapidly changing technological innovations that often change the way children are cared for [5, 7]. Therefore, paediatric nurses need to continually keep abreast of new knowledge and technical innovations, which however can generate new situations that are ethically challenging and paediatric nurses need specific ethical competences to overcome these new challenges [4]. These situations improve when nurses are directly involved in advanced paediatric critical care, in circumstances where they understand that they have the responsibility to decide what is best for the child [8] and to choose alternative options when the usual ones are no longer available [9]. In critical care, paediatric nurses should have the competences to identify, manage, and resolve ethical issues together with the patients and their families [10]. Therefore, nurses should also act as moral agents, who are accountable, consistent, and ethically responsible for judgments, decision making, and actions [11, 12]. All these aspects, linked to the nurses' attention, sensitivity, and communication skills, and their role as patient advocates, have a significant impact on the respect, protection, and implementation of children's rights [13].

Aim

To define what are the ethical dimensions and issues of paediatric nursing.

Methods

Search strategy

We conducted a review of the literature using the Rapid Evidence Assessment (REA) method [14, 15] to retrieve papers that focusing on the ethical dimensions of paediatric nursing, such as ethical competences. To optimize the search strategy, we followed a clinical question based on the PEO Methodology (Population and their problem, Exposure, Outcomes or themes) [16]. The population

included paediatric nurses or children's nurses; the exposure was 'paediatric clinical settings'; and the outcome was 'the ethical competencies and dimensions adopted by paediatric nurses while providing care'. We searched PubMed, SCOPUS, and CINAHL databases (see Table 1 for the search terms). Our search was limited to articles published in Italian and English between January 2001-March 2015.

Inclusion and exclusion criteria

Articles were included if they were: (a) related to ethical dimensions and/or methodological issues based on the PEO; (b) written in English or Italian; (c) with the abstract available. Articles were excluded if they were: (a) related to topics other than ethical dimensions or methodological issues; (b) grey literature and dissertations, methodological or theoretical descriptions or single case reports; (c) articles written in languages other than English or Italian; (d) studies about neonatal care. In line with the REA methodology, citations or key author searches were not taken into account and authors were not contacted.

Search outcomes

Initial screening

Our initial search of the databases produced a total of 1205 records. After removing 50 duplicate records, we had 1155 records. Two researchers separately read and checked that the respective titles and/or abstracts met the inclusion criteria. After excluding all the non-relevant papers, three researchers read the full texts and summarized the contents of each paper that met the inclusion criteria. The entire review process and the data analysis were supervised by the co-authors of the present review. Eight qualitative and two quantitative studies were included in the review following

the mixed method review criteria [17, 18, 19]. The identification and selection process of the present review was conducted according to the methodology suggested by the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) [20, 21] (Figure 1).

Overview of included studies

The papers included in this review were: two surveys, of which one was conducted in Israel [22], and one in the USA [23]; of the qualitative studies, two were conducted in Brazil [7, 13], one in Canada and Italy [8], one in Canada and France [24], one in Portugal [25], one in the USA [26], and one in Norway, which was split into two papers [4, 5] (Table 2).

The two quantitative studies [22, 23] used different investigative tools: The 'Ethical Dilemmas in Nursing' questionnaire (EDN), and a 45-item questionnaire, both developed by the authors of the studies. The other eight studies used qualitative methods: one was an exploratory study; one adopted a qualitative data analysis and semi-structured interviews; two applied a qualitative phenomenological approach; one was an ethnographic study; four did not specify the study design but two used a focus group methodology, and two adopted the narrative interview methodology. Regarding the characteristics of the sample, two studies included physicians and nurses [8, 24]. However, for the present review only the aspects related to nurses were considered.

Data extraction and synthesis

Data were extracted using an *ad hoc* tool based on the methodology suggested by the Institute of Medicine [27] and Long & Godfrey [28]. These tools included data, such as study design and aims, country of origin, setting, sample size, and representativeness. Two papers extracted relevant verbatim data related to paediatric nursing competences, discussed by the review team, and gathered

them into themes. Due to the heterogeneity and prevalence of the qualitative data, statistical techniques to synthesize them were not appropriate. A narrative synthesis of the extracted data was undertaken using results based on emerging themes to explore the relationships within and between selected studies [29].

Findings

Ethical issues in paediatric care

Some studies reported nurses' experiences of ethical issues arising from difficult situations in the field of paediatric care and their implications for practice. In Twomey's study, nurses described the ethical and moral issues associated with their relational and biomedical role with children, as well as with their role as advocates-facilitators between children and other professionals involved in their care. As a consequence, the environment (or milieu) becomes a sort of extension of the family because it becomes the source of ethical problems for all those who are part of it. With regard to the environment, the nurses balanced the patients' needs with the equally necessary requirement that the environment be preserved as a group entity. Here the nurses highlighted three different types of behavioural disorders in the field of mental health that can give rise to moral issues in nurses: escalation, de-escalation and seclusion. The nurses also reported also that when they were excluded by institutional rules this condition caused a strong pressure on them, influencing their caring relationships with the patients, as well as the nurses' individual integrity. Trust, fidelity, and mutual respect are key components of a caring relationship and for nurses it is important to define their own role towards the patient. Communication for nurses involved taking part in children's and their parents lives and becoming their voice when necessary [4]. Nurses, indeed, are often called to represent the values, beliefs, and choices of their patients and their parents in front of other professionals and institutions [22]. As professionals, nurses have to abide by their code of conduct [32]; however nurse are individuals with personal and professional values that may be in conflict with patient and/or institution one, generating ethical issues [2]. All these aspects could become sources of ethical issues when they clash with the nurses' beliefs, values, and the way they perceive their own role.

Sorlie et al. [4] also explored gender differences in difficult paediatric care situations. The authors found that for male nurses it was important to contemporaneously take care of children and their parents, clearly distinguish their own role from that of physicians when it came to dealing with drug therapies and decision making about life and death. For them, helping the patient was a fundamental value, where technology was important but not enough on its own. Other important components of caring were being close, comforting and protecting. The same authors in another part of their study also found that female nurses emphasized their feelings of loneliness and emotional pain due to the lack of an open dialogue with colleagues when there were issues related to justifiable practice and to the caring culture [4]. All these aspects have been described because, if left unaddressed, have the potential to develop ethical issues in nurses.

Wagner and Hendel (2000), in their survey highlighted another three important ethical issues linked to nursing: questioning treatments and the competences of physicians and nurses; lack of resources; and rude behaviours of some caregivers with patients. This study found that a frequent dilemma for nurses was the conflict between the needs of a patient and those of the family, and how and when it was possible to involve children in the decision-making process. Due to the particular nature of their work, paediatric nurses often felt stressed, tired, and with little human resources. The same nurses, underlined the importance of attending educational courses that can improve ethical decision making, gain a better understanding of their code of ethics, and of different cultures and beliefs. Although the paediatric nurses came from different countries and had different cultural backgrounds, when complying with universal values, they experienced similar ethical dilemmas [22].

Finally, the concept of vulnerability is another ethical aspect that emerged from the review. In Andrade's qualitative study (2013), the nurses' narratives about children's vulnerability were analysed. The commitment of professionals, especially of nurses, to the protection and defence of children is an ethical precept. Identifying situations of vulnerability in children offer nurses the occasion to get to know the children individually, the factors that cause health problems and risks, and expands the scope of nurses' attention to their family context. The principal elements of nursing care are: attention, sensitivity and communication abilities to affect care and health advocacy, to respect, protect and implement the rights of the child, and identify alternative solutions for the promotion of health [13].

Social responsibility

Some important aspects emerged from the study by Albuquerque Queiroz (2008), which explored the experience of nurses caring for severely ill children and their families. From the analysis of the relevant themes, they found that social responsibility and solidarity are important elements of nursing care for the non-biomedical dimensions experienced by children and families. They found that nurses gained a deeper feeling of their own self through their experiences and reflected more on their own values, increasing their ability to care in a more compassionate and holistic manner. In the study by Sorlie *et al.* [4] emerged also how important this aspect was for nurses in order to be considered as good professionals, but nurses also need to be recognized for the quality of their work when it fulfils the norms and roles of nurse group. They needed both a social confirmation and a self-confirmation. For these nurses it was important to remember their patients and to not forget to take good care of them. This can be described as a sort of ethical memory and nurses experienced 'emotional pain' when they understood that they had not paid enough attention to their young patients. Andrade and colleagues (2013) underlined how nurses should be considered as mediators in the child caring

process, a sort of agent who respects, protects, defends children's health, supports their families, and liaises with health services [13].

The decision-making process

In the last few years, there has been a dramatic increase in decisions to withhold or withdraw life-sustaining treatment in critically ill patients also in the field of paediatrics, giving rise to particular ethical problems. Burns et al. (2001) described the attitudes and practices of critical care nurses and physicians related to the limitation of life-sustaining treatment. Many factors need to be considered when deciding whether to forego or not life-sustaining treatment, such as patient-centred factors (e.g. quality of life as viewed by the patient or family) or financial costs for the society. The ethical issues regarding each patient should be discussed both within the team (i.e. physicians and nurses) and between the team and the family.

Another ethical issue is related to who should evaluate what is best for a child, as highlighted in the study by Carnevale et al. (2011). The nurses included in this study felt excluded from the decision-making process, and described how they could have contributed to the decision making process thanks to their privileged relationships with children and their families [8]. Carnevale et al. (2012) examined how physicians and nurses in France and Quebec could make decisions about life-sustaining therapies for critically ill children and about the ethical challenges these would entail. The most significant ethical challenges were: a) To study strategies and educational programs to improve team-family communication; b) Difficult relationships between physicians and nurses (some physicians attributed the silence of nurses in part to the low hierarchical level of their roles), resulting in a lack of participation in decision-making (This also depends on the cultural and organizational differences between countries), and c) Generating moral concern in nurses during decision making, to implement the decision-making process in an ethical manner.

Discussion

The purpose of this study was to conduct a Rapid Evidence Assessment (REA) to define the ethical dimensions or competences in paediatric nurses. We chose the REA method because it enables to identify in a reasonably short amount of time the principal ethical issues linked to paediatric nursing and to inform future research [14, 15]. Even if the REA method is quicker than a systematic review, it is not less rigorous, although there is always the risk of missing an important paper.

After analysing the studies included in this review, some general common areas emerged that highlighted paediatric nurses' distress caused by the need to make ethical decisions in critically intensive clinical settings. These macro areas were described as: a) 'ethically difficult healthcare situations'; b) 'decision making issues'; and c) 'social responsibility'. We found that the ethical issues encountered in paediatric nursing practice were in many aspects of a universal nature. Paediatric nurses seem to share ethical principles and values that are at the basis of nursing philosophy even across various cultural backgrounds [22]. The ultimate aim of this philosophy is to meet the needs of children and their families in a vision of global care based on the ethical principles of autonomy, beneficence, non-maleficence, and justice [7]. Nurses described compassion, care, patience, being able to listen, and the ability to recognise an emerging problem, and the most ethical action to undertake, as key ethical competences [7].

In agreement with Rodrigues et al. (2013), we reckon that it is important to implement programs dedicated to ethical decision-making, in compliance with the principles of the nursing code of conduct and bioethics, safeguarding moral behaviour. However, none of the studies included in our review provided a list of ethical competences specifically for paediatric nurses. This could be due to the fact that these competences are already embedded in the various nursing codes of ethics and conduct at

an international level, such as the International Council of Nurses (ICN) Ethical Code [22], American Academy of Pediatrics, Committee on Bioethics [31], Code of Ethics of the American Nurses Association [32]; or specific legislation, such as the Statute of the Child and Adolescent, as reported by Rodriguez et al. (2013). In addition, it is important to underline how ethics includes values, codes, and principles that rule decisions in the field of paediatric nursing practice and these should be considered as key aspects that inform professional education [22, 31, 32].

This aspect is underpinned by the fact that from our review emerged the importance of the role of paediatric nurses as mediators between the various health professionals involved in the healthcare process, with the duty to protect children's health and integrity [13, 26]. In this way, nurses' ethical behaviour becomes almost an imperative, which is often experienced with distress by nurses especially when they feel excluded from the decision making processes that concern them directly [8, 23, 24]. This aspect could be partly conditioned by the fact that the studies included in this review were mainly conducted in particular in the field of paediatric mental healthcare or in the area of critical care where the role of physicians is still predominant [8, 24, 26]. Other aspects that ethically weigh on nursing and that emerged from our review, are linked to problems related to communication processes and to situations of conflict between health professionals, children and their families, due to poor staffing, which compromises healthcare outcomes [22].

In addition, it is very important for paediatric nurses to be acknowledged as good professionals and at the same time have the possibility to share with the other members of the healthcare team ethically problematic situations that arise during clinical practice [4]. When this does not happen, paediatric nurses experience a strong sense of solitude and uneasiness [4, 5] especially those who work in the area of critical care [8, 23, 24]. In this context, as well as not being always directly involved in the decision making processes, paediatric nurses find themselves in difficulty when faced with situations contrast with the interests of a critically-ill child [8, 24].

Only one study described how and up to what point a child can be involved in the care process and in the decision making process [22], underlining that in paediatric nursing granting autonomy to a child can be a problem and can give rise to conflict with other health professionals and the family [22].

Another aspect analysed by the studies included in this REA was the health professionals' need for specific educational in the field of ethics [8, 22, 23, 25]. Nurses, as mediators, often represent the values, beliefs and preferences of the children and their families. In order to carry out this job in the best possible way, the relationship with the family and the other members of the healthcare team needs to be appropriately managed. Therefore, nurses are personally accountable to be systematically prepared for an ethical decision making process, to clarify their personal values and beliefs and be informed about contemporary ethical thought, professional guidelines, and the local and international ethical codes [8, 22, 23, 25].

Conclusions

Following our rapid evidence assessment (REA) we found that few studies had investigated the ethical dimensions of paediatric nursing. The studies included in our REA were prevalently conducted in critical care settings, therefore the data they analysed may not be relevant for other settings. From a methodological perspective, the selected studies were mainly qualitative, focused on nurses' perceptions and experiences, therefore due to their intrinsic nature they cannot be generalised. Little or nothing emerged regarding the importance of involving children in the healthcare and decision-making process, and also the role of the family is never clearly described.

Paediatric nurses would require specific educational interventions to help them resolve ethical issues, contribute to the decision making process, and fulfil their role as advocates of a vulnerable population such as sick children and their families. Further research is needed to investigate how paediatric nurses can improve the involvement of children and their families in decision making processes related to their own care plan.

All these aspects suggest the need to develop new studies that investigate the ethical competences of
paediatric nurses and how they can be improved through education and in various healthcare settings.

Conflict of interest

The authors declare that they have no potential conflicts of interest with respect to the present study, authorship, and publication of this paper.

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Table 1. Search strategy

Database Search strategy ("pediatric nurse") AND (ethical ISSUE) PubMed- MEDLINE (((((("Morals"[Mesh] OR "ethics" [Subheading] OR "Ethics"[Mesh])) OR (ethical issue*[Title/Abstract] OR ethical dilemma*[Title/Abstract] OR ethical principle*[Title/Abstract])) OR (moral decision[Title/Abstract] OR moral ("pediatric dilemma[Title/Abstract])))) AND nurse"[Title/Abstract] OR "child nurse"[Title/Abstract]) Filters: Abstract; Publication date from 2000/01/01 to 2015/03/31 (((Pediatric Nursing [MeSH Terms] OR Infant [MeSH Terms] OR Child [MeSH Terms] OR Adolescent [MeSH Terms] OR Pediatric [Title/Abstract])) Nursing AND (((Ethic*[nurs*[Title/Abstract]) **AND** Title/Abstract]) OR Moral*[Title/Abstract] OR Dilemma*[Title/Abstract] OR Authonomy [Title/Abstract] OR Justice [Title/Abstract] OR Integrity [Title/Abstract] OR Respect*

Wisdom

[Title/Abstract]

[Title/Abstract]

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[Title/Abstract]))

[Title/Abstract])

Italian[lang]))))

competence

competence[MeSH

competence[MeSH

CINAHL

(Ethic* OR Moral* OR Dilemma* OR Autonomy OR Justice OR Integrity OR Respect* OR Trust* OR Wisdom OR Courage OR Beneficence OR Non-maleficence OR Deontology) AND (pediatric nurs* OR child nurs*)

[Title/Abstract] OR Trust* [Title/Abstract] OR

OR

AND

competence[Title/Abstract]) OR professional

(hasabstract[text] AND ("2000/01/01"[PDat] : "2015/03/31"[PDat]) AND Humans[Mesh] AND (English[lang] OR French[lang] OR

OR

OR

Terms])

Terms])

[Title/Abstract]))))

OR

OR

OR

OR

Courage

Beneficence

deontology ((((((professional

clinical

clinical

skill

Non-maleficence

[Title/Abstract]

Filters: Abstract; Publication date from 2000/01/01 to 2015/03/31

Nursing/Health professional research articles: SCOPUS

(TITLE-ABS-KEY (ethic* OR moral* OR dilemma* OR autonomy OR justice OR integrity OR respect* OR trust* OR wisdom OR courage OR beneficence OR nonmaleficence OR deontology) AND TITLE-ABS-KEY (pediatric nurse OR child nurse)) AND PUBYEAR > 1999 AND (LIMIT-TO (DOCTYPE, "ar") OR LIMIT-TO (DOCTYPE , "ip")) AND (LIMIT-TO (LANGUAGE , "English")) AND (LIMIT-TO (SUBJAREA, "MEDI") OR LIMIT-TO (SUBJAREA, "NURS") OR LIMIT-TO (SUBJAREA, "HEAL")) (TITLE-ABS-KEY ((ethic* OR moral* OR dilemma* OR autonomy OR justice OR integrity OR respect* OR trust* OR wisdom OR courage OR beneficence OR nonmaleficence OR deontology)) AND TITLE-ABS-KEY (pediatric nurse OR child nurse) AND TITLE-ABS-KEY (professional competence OR clinical competence OR skill OR clinical competence OR professional competence)) AND PUBYEAR > 2000 AND (LIMIT-TO (DOCTYPE, "ar")) AND (LIMIT-TO (LANGUAGE, "English") OR LIMIT-TO (LANGUAGE, "French") OR LIMIT-TO (LANGUAGE, "Italian"))

Table 2. Characteristics of included studies

REFERE NCE, COUNTR Y	AIM	STUDY DESIGN/ METHODOLOGY	SAMPLE DESCRIPTION
Andrade et al 2013, Brazil	To analyze nurses' reports on child care during well-baby care, taking into consideration the care and defense of the right to health.	Exploratory qualitative study/Semi structured interviews recorded	14 nurses (male=2; female=12), Age range=29-48
Burns et al 2001, USA	To describe the attitudes and practices of critical care physicians and nurses regarding limitations to life sustaining treatment. To report the personal and professional characteristics associated with particular attitudes on these issues.	Cross-sectional survey/Questionnaire	110 physicians and 92 nurses Mean age nurses=30yrs, Mean age physician=39yrs
Carnevale et al. 2011 Canada and Italy	Describe how decisions are made in the treatment of life support (LST) in critically ill children and how these decision -making processes are experienced by the team and parents.	Qualitative research/Focus group	16 physicians age range 42, range of PICU experience 13; 26 nurses, all female, age range 42, range of PICU experience 10; 9 parents (7 mother and 2 father)
Carnevale et al., 2012 Canada and France	examined how physicians and nurses in France and Quebec make decisions about life- sustaining therapies (LSTs) for critically ill children and corresponding ethical challenges	Qualitative research/Focus group	Canada: 10 (male= 2, female=8), age range 25-50, range of PICU experience 2.5-25. France: 14 (male=1, female=13) age range 22-45, range of PICU experience 0.17-19.
Queiroz 2008, Portugal	To identify the significant elements of the experiences of professionals who are members of nursing teams in the inpatient units of a paediatric hospital in the centre of Portugal.	Exploratory study using a qualitative phenomenological and hermeneutic approach/Focus group	11 nurses (No reported sample characteristics)

Rodrigues et al 2013 Brazil	To examine comprehensively how the nurse inserts the ethics and bioethics in the care of the child and his family within the hospitals.	Phenomenological study/Interview	9 nurses. (No reported sample characteristics)
Sørlie et al 2003, Norway	Investigation of the meaning of being in ethically difficult situations in pediatric care by male Rns.	Qualitative research/Narrative interview	5 male RN, age range 32 y, age range of the experiences in paediatric clinics 1-7 years, and in health care 1-11 years.
Sørlie et al 2003, Norway	illuminate the meaning of female RN lived experience of being in ethically difficult care situations in paediatric care	Qualitative research/Narrative interviews	20 female RN, age range 25-48, age range of experience in paediatric clinics 10 nurses had a range 5-25 years; 10 nurses had a range 2 mounth-5 years.
Twomey 2000, USA	Identify which ethical issues arise in pediatric mental health nursing	Ethnographic research/Unstructured Interview	20 RN (male=2, female=18), mean experience duration in pediatric mental health 6 years.
Wagner & Hendel 2000, Israel	to identify and compare ethical situations that the two groups of nurses encounter, (2) to assess the nurses' familiarity with the International Council of Nurses (ICN) ethical code, (3) to identify factors influencing nurses' ethical beliefs, (4) to identify and compare the resources for support, (5) to identify causes of ethical dilemmas.	Quantitative research/ Questionnaire	224 nurses: 169 Israeli nurses (mean age 38.6; mean worked year 13.8); 55 international nurses (mean age 34.4; mean worked year 10.3)

Figure 1. Flow diagram of the literature review process (PRISMA 2009)

