Neonatology and the end-of-life: the bioethics implications related to health team-patient-family

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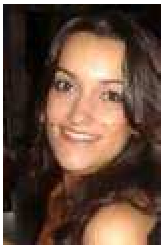

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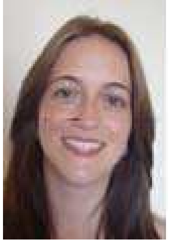

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Abstract

This study aims at knowing what represents the terminal neonate patient to the health team, as well as regarding their relation to terminal neonate patient and his family. The method chosen was the qualitative-descriptive type, and methodological guidelines based on Collective Subject Discourse. The study interviewed twenty health professionals, ages over twenty-five-years old, responsible for the terminal neonate patients' treatment and care, working in medium size hospital in the town of Pouso Alegre (MG). The results reinforce that the conflict between the professional personality and the health area's reality guides the health team-terminal neonate patient-family relationship, inducing the health team to see their own presence as embarrassing and useless, next the patient's family. However, the bioethical principles about the end of life overlap the patient's family right of knowing the truth, and establish that, in face of the right to the dialogue with the team, the personification of the health team-terminal neonate patient stands as the ethical essence of this relationship.

Key-words: Physician-patient relations. Terminally ill. Neonatology. Bioethics.

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Neonatology is a branch of Pediatrics, which extends medical care beyond labor and offers treatment to newborns and nurslings that might need care. Ever since its first appearance in France in 1882 at the hands of obstetrician, Pierre Budin [1-3], the neonatal period is characterized by the great fragility of the human-being, as well as the high risk of sequelae - which in many cases cause disability, lasting long periods of time, and high rates of morbimortality [2,3].

With a view to improving these rates, neonatology is one of the health fields that most deserves credit for its practical application of the ideologies of the third industrial revolution. At the end of the 19th century and start of the 20th, great changes took place in the neonatal care practices [3,4] due to use technology, enabling a better understanding of newborn's physiology, the introduction of efficient equipment to ensure survival, the development of effective medicines and the applications of better approaches in the treatment of neonates.

Besides altering therapy in the health area, the technological revolution also transformed the nature of communication in medical practice. Health education defends objective discourse and communication based on medical evidence, for the *effectiveness* of health team conclusions to underpin unquestionably their conduct [5,6].

The biggest potential for cure observed, currently, in the intensive pediatric care units (neonatal ICU) results from the incorporation of novel technology to the vital support in neonatology and the adaptation of health professionals to the these technologies. These same circumstances retard discussion of life terminality issues by this same team [7,8]. However, according to Santos [9], contrarily to other sectors of a hospital unit, and even with all the technological innovation, the neonatal ICU present higher death incidence, for neonates are more vulnerable and unstable, but have higher chance of survival.

With this data in hand, one observes that, together with newborns, family members experiment diverse sensations at this difficult time, focused on the therapeutic possibilities that many times are in vain. The seriously ill neonate becomes the very core of parental life, whose most urgent necessity is information on its clinical status and prognostic. Parents desperately look for signs of life continuity for their infant, as well as if there will be sequelae due to the illness in question. They anxiously want to know the reason for all interventions, questioning health team on patient's pain sensibility and hearing sense, even when unawake.

In neonatology, the application of bioethical principialist principles – *beneficence, non-maleficence, autonomy, and justice* – can minimize the suffering inherent to this scenario. In reference to *beneficence* and *non-maleficence*, accordingly to the provisions of medical deontological, *good deeds* expresses such application, which translates into moral obligation of acting in benefit of the person, as well as not harming this person. In the case of neonatal terminality, the triangular relation health team-patient-family illustrates the principles of beneficence and non- maleficence, when, through dialogue, there is personalized relationship between the professional and patient's family, seeking the best results for the patient. This movement tends to attenuate the agony of family members in face of infant death, especially due to the method the doctor uses to present the diagnosis and to provide further all the additional information the family might request [10-13].

How the professional interacts with the family members in the stages that involve neonate terminality can have substantial impact on the way they digest and experience the painful process. Urban [14] reports that in ICU, the action of patient and health professional must be immediate and the supplementations to treatment must be fast and essential, directed exclusively towards the patient. In this context of urgent care, attention to the family is put on a back burner.

Despite the unquestionable need to provide care with due expedition, subjective aspects pertaining to the interrelation between professionals and family cannot go unwatched, as they contribute plenty to the improvement of the service offered in the neonatal ICU. Considering the cited presuppositions of clinical bioethics, the health professional must act both in the sense of guaranteeing the best therapeutic response, which refers to their technical improvement, but also in the development of relationship skills that characterize human contact and complement the attributes of a good professional.

In this way, Poles [15] stresses that the health team must go on fulfilling their role even when faced with inevitable death. It is mainly in those situations, in which there is no possibility of curbing neonatal death, the family needs special attention and care – for them to experience this moment in the most dignified way. Even though death is a common event in the daily reality of health professionals, they have a hard time accepting and managing this situation in a suitable way, particularly because it involves an infant and its family.

In relation to the principle of autonomy, the examples of neonatal ICU are of paradigmatic importance for studying cases of reduced autonomy or for those cases marked by total lack of such capacity, given that the newborn cannot exercise autonomy for therapeutic decisions and thus it is transferred to the parents or legal guardians. When fully informed, they can advocate rationally a conduct to follow. However, professional team, having recourse of medical autonomy, may not accept family's decision that It does not favor the child. When this sort of deadlock appears, the issue is solved by ethical or legal commissions [8], which evaluate impact and cost-benefit ratio of proposed therapy for the patient.

The principle of justice reveals itself when therapeutical decisions are made in medical and not economic basis, that is, one prevents that problems deriving from limited economic resources jeopardize treatment. Chapter I, Items VI and XVI, of the 2009 Medical Ethical Code, based in these principles, evidences as morally acceptable, due to finite resources, the non indication of advance support to life, as long as patients are classified, with certainty, as without favorable prognosis. In such context, physician-patient-family relationship should be in the center of attention when seeking a treatment plan that prioritizes patient's comfort, and identification of suitable treatment possibilities at the time [16]. It is indispensable that family has access to needed clarification to understand patient's clinical picture and technical criteria previously discusses, which are the basis for deliberation on the irreversibility of the case. This information will allow for adoption of recommended therapeutic be a joint decision of the assisting team and family, lessening the suffering of all involved.

In this sense, Pedroso [17] states that hearing and listening closely becomes an essential instrument for the health team to learn how to understand the other person and understand their singularities. And so, it is fundamental to enter the world of *being*, and see life through their conceptions and listen with care to their experiences. With this understanding, derived from the study of communication, postures, and conducts, the neonatal ICU health team will be capable of dealing with genuinely tough situations, addressing the real necessities of the persons (patient and family) under care, as well as themselves. The realist vision of the illness and a clear conscience of the importance of the application of a physician-patient-family relationship model, based on bioethical principles, result in fair appreciation of all components of a terminal situation and reinforce that, even when clinical treatment has reached its limit, the ethical sense of the relationship must prevail [18].

Method

Considering the nature of this study, a descriptive research of qualitative approach was chosen. The major focus of descriptive research is the description of the features of certain populations or phenomena, as well as the description of a process within an organization, the analysis of the service level of entities, polls of opinion, attitudes, beliefs of a given population etc. Minayo [19] believes qualitative research responds to particular questions, regarding the study subject as people belonging to a group and with a determined social condition, in a universe of meanings, values, beliefs, and attitudes. This study is descriptive and used a qualitative approach.

The theory of social representations (TRS) was employed as methodological reference, as described by Moscovici in 1978 [20] – which presents great adherence to objects of study in the health field, for it is able to grasp the subjective aspects that permeate the problems inherent to the field. To understand and describe the meanings of the considerations made by doctors with respect to the terminal patients and to assess their attitude towards life terminality, under the TRS reference, the collective subject discourse (DSC) was adopted the analytical method, for allowing the approximation to the phenomenon under analysis.

Semi-structured, individual interviews were carried out, with the signing of the voluntary and clear consent term (TCLE), in observance to Resolution 196/96 of the National Health Council, which deals with researches involving humans. Its directives guided the ethical issues concerning this project, which were informed to the interviewees by the surveyor [21]. The study was approved by the Ethics Committee on Research of the University of the Sapucai Valley of Pouso Alegre (Univas).

The survey was conducted in the period from March 1, 2009, to February 28, 2010. The participants were health team members (physicians, nurses, nursing technicians, physiotherapists, and psychologists), of both genders (5 men, 15 women) with 25 years of age or more (respecting the minimum age limit for working at the hospital where the research was conducted), that served in neonatal ICU of a regional public hospital in the city of Pouso Alegre, Minas Gerais. The interview investigated the perceptions in relations to the triangular relationship physician-terminal neonate patient-family and its inherent bioethical conflicts. Each interview was recorded and transcribed for analysis. For analysis and presentation of the results the DSC was utilized, written in the first person singular, composed of key expressions (ECH), that had the same central ideas (IC) and same anchorage (AC), observing with rigor the order of the following stages:

> 1st stage: the answers were heard several times and only after better understanding of the general idea of the discourse, were they actually literally transcribed;
> 2nd stage: complete reading of the answers given by the interviewees, followed by separate reading of all answers for the question being analyzed;
> 3rd stage: transcription of answers to question 1, with markings in Italics for ECH and indications for IC that represent the description of the ECH and not its interpretation. Same procedure for all questions;
> 4th stage: individual transcription of each central idea with its respective ECH;
> 5th stage: extraction of the topic of each of the questions, grouping their respective IC, subjects, represented by the number of interviewees, and the frequency of ideas in graphs. Finally, the DSC were built separately from each central idea, with its respective ECH.

Results

The results from the semi-structured research were collected from the reports of team members, grouped and analyzes in term of the answers to the questions: “*What does a terminal neonate patient represent to you?*”…; “*What does it mean the relationship health team-terminal neonate patient?;* and of the “*relationship health team-family of the terminal neonate?”*

The first question showed the following results: eight central ideas: frustration (7); challenge (3); patient that requires special care (3); normal (2); a being that completed its cycle (2); dignified death (1); heard (1); serious (1), out of a total of 20 ideas. Within the eight central ideas found, *frustration* presented the highest frequency at 35%, followed by challenge at 15%, and patient that requires special care at 15%. The smallest frequency rates were presented by dignified death at 5%, hard at 5%, serious at 5%, as illustrated by Table 1.

Table 1. Considerations on terminal neonate patients

Central idea	Subject	Frequency
Frustration	2, 5, 6, 10, 13, 17, 19	7
Challenge	7, 8, 9	3
Patient with special needs	12, 15, 14	3
Normal	18, 20	2
Completion of cycle by the being	3, 4	2
Dignified death	16	1
Hard	11	1
Serious	1	1
Total		20

*Refers to the question *“What does a terminal neonate patient represent to you?”*

Moreira Filho [10] writes that the physician-patient contact is a very specific relationship, for the presence or possibility of a disease invests it with characteristics hardly found in other human relations. At all times, physicians are faced with the unpredictable nature of the human-being, the imperfections of science, our own limitations, the reality of pain, and the questionings about death. This agony repeats itself in every contact with a new patient and it only goes unperceived because physicians having experienced it over and over again, elaborate mechanisms, not always healthy, to confront it. This repetition of feelings extends to health team as a whole and it can be observed in the discourse of the central ideas *frustration* and *challenge,* respectively the most frequent ones:

> “*It represents a frustration, because there is nothing else to be done, medical resources were depleted, and the newborn did not correspond. He does not respond in spite of all the medication and therapy. All assistance from the team was not sufficient for him to recover*”*.*
>
> *“It represents a great challenge. It induces us to work harder, to invest more.”*

Preparation at university in Health Sciences prioritizes a profile towards objectivity, with more attention given to physical abnormalities and to laboratorial exams. However, the practical reality of the health team, in confronting with the suffering and insecurity in face of illness and the constant presence of death, provokes a forced acknowledgment of scientific limitation and the limitations of the professional themselves. The result of the confrontation between this professional profiles, acquired during academic formation, and the limitations of their practical reality impacts directly the patient and family, which are the targets of professional action [10].

The observations regarding the first question of this study reinforce the idea that even though all the necessary clinical support to alleviate pain and discomfort for the terminal newborn patient is provided, the recognition of therapeutic .limitation (once the irreversible diagnosis is confirmed) causes frustration to the professional, resultant from the forced acknowledgment of their own limitation. This situation leads the team to ponder their useless and embarrassing bedside presence, inducing them to a technical posture in face of the terminal neonate patient and isolation from the family.

The study also found the refusal by the health team to acknowledge their professional limitation. This hardship manifested by professionals de-personifies the terminal patient by classifying them as just another therapeutic challenge to be *solved* at any cost [10,13]. The Work of Gutierrez [22] demonstrates that the findings of this study are not an isolated fact. Plenty health teams resolve this delicate issue by removing the personal approach from the contact with the ill and their family members, acquiring a growing ability at maintaining distance from subjective aspects of the physician-patient relationship.

The second question, which versed about "*the health team relation with terminal neonate patient and patient's family"*, presented six central ideas. The majority of answers (16) evidences *the difficulty of taking a stance in face of neonate terminality*. The following categories were considered: technique (7), distant (4), difficult (3), and complicated (2). The other central ideas found in the interviews that do not belong to any of the abovementioned groups were: important (2) and humanization (2), which totaled only four answers. As in the last question, the total of central ideas is equal to 20 (Table 2).

Table 2. Relation of health team-terminal neonate patient and family

Central idea	Subject	Frequency
Technique	5, 7, 9, 14, 15, 18, 20	7
Distant	4, 8, 17, 19	4
Hard	6, 10, 11	3
Complicated	1, 3	2
Important	2, 16	2
Humanization	12, 13	2
Total		20

* It refers to questions: "*What does it mean the relationship health team-terminal neonate patient for you?* and "the *relationship health team-family of the terminal neonate?"*

Confirming the analysis carried out in relation to the first question of this study, frustration, resultant from the forced acknowledgement of therapeutic limitation and medical action, as well as the irreversibility of the condition, lead the team to adopt a health team-terminal neonate patient relationship characterized by professionalism and distance, which can be observed in the reports that follow:

> "*It is a very technical relationship, as to not get emotionally involved. The trust of the family must be won, but through a relation of professionalism."*
>
> *"Despite their expertise, all team members become uneasy. All the necessary support is provided, but everyone gets apprehensive. When we know there will not be progress and that there is nothing else to be done, sometimes involvement is negated, everybody drifts apart, and there is even less involvement with the family. They realize we disperse".*

Still, bearing in mind the conflict between professional profile and health team reality, the analysis of the first question related to team's refusal to acknowledge therapeutic limitation and their professional limitation, establishing a therapeutic challenge to be *solved,* is reinforced by the answers of this second question related to health team's hardship to establish a relationship with terminal neonate patient and his family:

> "*It is harder because when dealing with the newborn we do not have a strong connection. And with the family, we feel that it is a more delicate process to be handled. So it is hard, it is a delicate situation, one does not know what to say".*

One datum that deserved highlight in the analysis of this question relates to the fact that only 5% of the interviewees cited humanization concept to characterize the relation between health team-terminal neonate patient and family. As verified in the discourse that follows, the central idea *humanization* also reflects the agony in face of the irreversibility of the clinical condition of the newborn and agony of its family:

> "*It is a human relation, you cannot be solely technical, and you must be compassionate and love for the other, in an attempt to better save their life. In relation to the family, we provide the necessary support trying to attenuate the situation in face of suffering. The family, sometimes, sees us as the answer to all their problems, as if we were an extension of the mother and thus we must take care of the infant".*

Campos [23] states that humanization involves a reform that can combine scientific objectiveness of the health/illness/intervention process, incorporating the individual and his history from the moment of diagnosis until the intervention. For Benevides and Passos [24], humanization corresponds to the altering of how we do, work, and produce in health field with a view to surpassing the frontiers of the different centers of knowledge/power that are occupied with producing health. The results obtained from this study, which aimed at investigating the conceptions and professional behavior in face of life terminality, reveal that reform and the necessary changes for humanization, emphasized by these authors, are still not practiced by all professionals of the health team that attend to a terminal neonate patient and its family. Conflict between the professional profile (classic objectivism) and health team's reality of the (its limitations) guide the relationship between health team-terminal neonate patient and family.

Discussion

Bioethics emerges in a scientific context as reflection on everything that interferes in the respect for life quality and dignity, representing the recuperation of ethics, full citizenship, and respect for differences. The present study found that most interviewees constantly infringe all principles of principialist bioethics, by insisting on the objective aspects of the relationship between health team-terminal neonate patient and family (objectivism resulting from insecurity in face of ethical issues that involve life terminality), given that they deny patients a effectively personalized contact, which should avoid all therapeutic formalism and respect patient individuality and the family members' distress, considering their thoughts and aspirations. Finally, a relation in which dialogue between health team and patient's family collaborates for comfort, support, and trust provision to patient and his family [10,12,13].

Given the specific conditions of neonatal terminality, the study found that beneficence, non-maleficence, autonomy, and justice are blended in an inextricable manner in the dilemmas experienced daily at neonatal ICU. Autonomy, when in the context of neonatal terminality is the frailest of these principles, usually seen and practiced as if it was the right of the family to know the truth about the patient, founded on the use of informed consent, essential prerequisite to ensuring the application of this principle. However, in the context of neonatal terminality, the application of the autonomy principle becomes real when the health team is able to define the best therapy to be administered jointly with the family. The dialogue between the team and family fosters not only respect for autonomy, but it also includes the principle of beneficence [25-27].

The weakness caused by the illness, which worsens evermore with time, makes life finitude more tangible in a terminality scenario. As the confined limits are surpassed, the biological dimension of medical intervention, the relationship between health team-terminal and neonate patient must take on a deeper dimension. The professional attitude based exclusively on technique, many times adopted in face of neonate terminality, leads to isolation from the family of the patient. It is learned that the existence of such attitude denotes frustration in face of therapeutic limitation, which seem to indicate negative self-assessment of their own action as professionals. This mix of emotions, feelings, and ideas expose the patient to inadequate and, sometimes, disrespectful conducts, besides eliminating the possibility of dialogue between family and health team, depriving them of a dignified relationship [10].

Most interviewees in this study believe their mission is to heal. However, according to the sayings to Hippocrates, the physician's obligation (in this case, the team's) is treating whenever possible and caring always [2]. This caring can be associated to the beneficence and autonomy principles, represented by the presence of the health team together with the patient, in an attempt to establish a mutual relation, which avoids dispersonification of this relation. These principles are reinforced by clinical practice by means of respecting the wish of the patient's family to speak, to be heard, to obtain answers for their preoccupations in a moment where every event, word, thought, purpose, decision, and attitude takes on a whole new meaning [18].

With humanized care to the terminal neonate patient and its family, it can be avoided that the patient be perceived as a challenge to be solved - condition that might lead to the application of inadequate and disrespectful therapies - to elevate professional prestige of the health team, which further infringes the principles of non-maleficence and justice. In this case, in face of patient's family need to see itself through the eyes of the team, to evaluate the situation and manage their relation with the disease of the terminal neonate patient, the bioethical principles of non-maleficence and justice further strengthens the already detected need to develop a relationship based on reciprocity, which permits avoiding patient's dispersonification [18].

The analysis of the surveyed discourse in this work, which show the frustration and the emphasis of the professionals in the reaffirmation of technique in face of neonatal terminality, confirms previous studies [10, 11, 15, 17], which point out, firstly, it is essential to hold talks between health team and family to seek consensus in relation to the patient. Only then other possible conducts can be discussed. Present investigation data also indicates that objectives must be common between family members and the health team, always focusing on reciprocity relationship based on dialogue between both parties, to minimize health team's discomfort feelings in face of the patient and, thus, enabling them to act jointly with the family in the most suitable way to each case, concerning the principles set forth by bioethics. The understanding of the meaning of the discourse by interviewees provides signs that the goal of mutual decision is that comfort and less suffering to the patient (and consequently to the family) will effectively become the main and first therapy to be adopted [18].

Final Considerations

With all the technical devices that augment observation power in the health areas, none comes close to the value and skillful use of listening, paying attention, and speaking words – words from the health team and words from patient and family. When it is understood that this form of relationship is important, then the handling of situations involving fragility and therapeutic limit, in face of a constant presence of death, would attend the real needs for caring of the patient and health team themselves. In all fields of medicine this skill still is one of the main techniques of diagnosis and in therapy, even with all the chemical and mechanical aids, still it plays an essential role.

The technological progress applied to medicine has created the theoretical possibility to retard death indefinitely. However, the data collected by this study suggests technological progress induces professionals to technical objectivism and insecurity when dealing with their limitations. Data also points to how pungent the feelings related to life terminality can be, even to those who are trained to deal with it, and how academic formation focused on technique over human values and feelings offers no contribution for the health team to realize there was a another human being in front of them [10].

In light of the results from this survey, it can be reaffirmed that dialogue not only represents respect to the patient and family dignity, in line with the principialist bioethical and human rights principles, but also represents a fundamental strategy to aid the health team understand the processes that the family of the terminal neonate experiences [10]. Personification of health team-terminal neonate patient relationship stands as the ethical essence of this relationship, which reinforces health team's duty to heal sometimes, to alleviate often, and to comfort always [10], establishing that, when clinical treatment has reach its limit, the ethical sense of the relationship must prevail to consolidate, also at time of death, the inherent dignity of the human person [18].

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Resumo

Neonatologia e terminalidade da vida: as implicações bioéticas da relação equipe de saúde-paciente-família

Objetivou-se conhecer o que representa o paciente neonato terminal para a equipe de saúde, bem como a relação desta com o paciente neonato terminal e sua família. Com método qualitativo-descritivo e diretriz metodológica do discurso do sujeito coletivo, entrevistou-se 20 profissionais de saúde, maiores de 25 anos, responsáveis pelo tratamento e cuidado de pacientes neonatos em fase terminal, atuantes em hospital de médio porte da cidade de Pouso Alegre (MG). Os resultados encontrados reforçam que o conflito entre a personalidade profissional e a realidade da área da saúde norteia a relação equipe de saúde-paciente neonato terminal-família, induzindo a equipe a julgar a própria presença como embaraçosa e inútil junto à família deste paciente. Porém, os princípios bioéticos na terminalidade da vida ultrapassam o direito dos familiares à verdade e estabelecem que, mediante o direito ao diálogo com a equipe, a personificação da relação equipe de saúde-paciente neonato terminal se firme como essência ética desta relação.

Palavras-chave: Relações médico-paciente. Doente terminal. Neonatologia. Bioética.

Resumen

Neonatología y fin de la vida: las consecuencias de la bioética en las relaciones equipo de salud-paciente-familia

Este estudio investigó la representación del enfermo terminal recién nacido al equipo de salud, y evaluados su actitud hacia el final de la vida. El método fue el tipo cualitativo-descriptivo, con marco metodológico del Discurso del Sujeto Colectivo. Se entrevistó a 20 profesionales de la salud, mayores de 25 años, responsables del tratamiento de los pacientes terminales recién nacido, que trabajan en el HCSL, Pouso Alegre, en Brasil. Los resultados refuerzan que el conflicto entre la personalidad y la realidad profesional del área de salud orienta la relación del equipo de salud recién nacido terminal-familia, lo que dirigió el equipo a juzgar su presencia incómoda e inútil con la familia de los pacientes. Sin embargo, los principios bioéticos en la terminal de la vida no se limitan sólo al derecho de los familiares a la verdad, sino también a establecer el derecho al diálogo con su equipo como la esencia de esta relación.

Palabras clave: Relación médico-paciente. Enfermo terminal. Neonatología. Bioética

References

1. Avery GB. Neonatologia: fisiopatologia e tratamento do recém-nascido. 2a ed. Rio de Janeiro: Medsi; 1984.
2. Alencar AJC, Rolim KMC. Bases científicas do acolhimento amoroso ao recém-nascido. Rev Ped Ce 2006;7(1):27-32.
3. Oliveira ICS, Rodrigues RG. Assistencia ao recém-nascido: perspectivas para o saber de enfermagem em neonatologia (1937-1979). Texto Contexto Enfermagem [internet] 2005 [acesso 13 set 2008];14(4):498-505. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072005000400005&lng=pt.
4. Sá Neto JA, Rodrigues BMRD. Tecnologia como fundamento do cuidar em neonatologia. [online]. Texto Contexto Enfermagem [internet] 2010 [acesso 17 nov 2010];19(2):372-7. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072010000200020&lng=en.doi:10.1590/S0104-07072010000200020.
5. Stepke FL. Bioética e medicina: aspectos de uma relaçao. Sao Paulo: Loyola; 2006.
6. Torres WC. A bioética e a psicologia da saúde: reflexoes sobre questoes de vida e morte. Psicol Reflex Crít [internet] 2003 [acesso 12 set 2008]; 16(3): 475-482. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-79722003000300006&lng=pt&nrm=iso.
7. Soares M, Terzi RGG, Piva JP. Terminalidade da vida e cuidados de final de vida na unidade de terapia intensiva [online]. Rev Bras Ter Intensiva [internet] 2007 [acesso 25 jul 2008];19(3):357-8. (Série temática) Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-507X2007000300016&lng=pt&nrm=iso.
8. Lago PM, Garros D, Piva JP. Terminalidade e condutas de final de vida em unidades de terapia intensiva pediátrica. Rev Bras Ter Intensiva [internet] 2007 [acesso 25 jul 2008];19(3):359-63. Disponível: http://www.scielo.br/scielo.php?script=sci_ arttext&pid=S0103-507X2007000300017&lng=en&nrm=iso.
9. Santos FS, Incontri D. A arte de morrer: visoes plurais. Bragança Paulista: Comenius; 2007.
10. Moreira Filho AA. Relaçao médico-paciente. teoria e prática, o fundamento mais importante da prática médica. 2a ed. Belo Horizonte: Coopmed, CRM-MG; 2005.
11. Kubler-Ross E. Sobre a morte e o morrer. 8a ed. Sao Paulo: Martins Fontes;1998.
12. Silva LC, Anjos AR. Aconselhamento genético: reflexoes bioéticas sobre as relaçoes entre genes, doenças genéticas e discriminaçao genética. In: Salles AA, organizador. Bioética reflexoes interdisciplinares. Belo Horizonte: Mazza; 2010. p. 145-52.
13. Mascarenhas NB, Rosa DOS. Bioética e formaçao do enfermeiro: uma interface necessária.Texto Contexto Enfermagem [internet] 2010 [acesso 17 nov 2010];19(2):366-71. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072010000200019&lng=en. doi: 10.1590/S0104-07072010000200019.

14. CA. Bioética clínica. Rio de Janeiro: Revinter; 2003.
15. Poles K, Bousso RS. Compartilhando o processo de morte com a família: a experiencia da enfermeira na UTI pediátrica. Rev Latinoam Enferm 2006;14(2):207-13.
16. Conselho Federal de Medicina. Código de Ética Médica: Resoluçao CFM no 1.931, de 17 de setembro de 2009 (versao de bolso). Brasília: CFM; 2010. p. 10.
17. Pedroso GER, Bousso RS. O significado de cuidar da família na UTI neonatal: crenças da equipe de enfermagem. Cienc Cuid Saúde 2003;2(2):123-9.
18. Silva FL. Direitos e deveres do paciente terminal. Bioética 1993;1(2):139-43.
19. Minayo MCS. Pesquisa social: teoria, método e criatividade. 17a ed. Petrópolis: Vozes; 1994.
20. Moscovici S. Representaçao social da psicanálise. Rio de Janeiro: Zahar; 1978.
21. Alves E. Termo de consentimento livre e esclarecido. Ética Revista 2005;3(2):26-7.
22. Gutierrez PL. O que é o paciente terminal? [online]. Rev Assoc Méd Bras [internet] 2001 [acesso 15 fev 2007];47(2):92. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-42302001000200010&lng=pt. doi: 10.1590/S0104-42302001000200010.
23. Campos GWS. Humanizaçao da saúde: um projeto em defesa da vida. Interface [internet] 2005 [acesso 15 mar 2009];9(17):398-400. Disponível: http://www.scielo.br/pdf/icse/v9n17/v9n17a16.pdf.
24. Benevides R, Passos E. A humanizaçao como dimensao pública das políticas de saúde. Cienc Saúde Coletiva [internet] 2005 [acesso 10 dez 2008];10(3):561-71. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232005000300014&lng=pt.
25. Vianna LG, Vianna C, Bezerra AJC. Relaçao médico-paciente idoso: desafios e perspectivas.Rev Bras Educ Méd [internet] 2010 [acesso 17 nov 2010];34(1):150-9. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0100-55022010000100018&lng=en&nrm=iso. doi: 10.1590/S0100-55022010000100018.
26. Costa R, Padilha MI, Monticelli M. Produçao de conhecimento sobre o cuidado ao recém nascido em UTI neonatal: contribuiçao da enfermagem brasileira. Rev Esc Enferm USP [internet] 2010 [acesso 17 nov 2010];44(1):199-204. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342010000100028&lng=en. doi: 10.1590/S0080-62342010000100028.
27. Oliveira RA, Jorge Filho I. Bioética clínica: como praticá-la? Rev Col Brás Cir [internet] 2010 [acesso 17 nov 2010];37(3):245-6. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0100-9912010000300014&lng=en. doi: 10.1590/S0100-69912010000300014.

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