

Breaking Bad News: From Brain Death to Organ Donation

— A Case Report

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Abstract: Organ transplantation is a treatment modality that consists in the replacement of a diseased organ by a healthy one. Organ donation is historically linked to the attempt to preserve life. One of the greatest difficulties in dealing with the death subject is precisely related to healthcare contexts: the scientific advances in healthcare are associated with an increase in life expectancy and the idea of a possible gradual deferral of death. Part of the transplantation process is a Brain Death (BD) diagnosis, which is necessary for organ donation. J. was an ICU inpatient who, after a few days of hospitalization, ended up evolving to a DB diagnosis. The patient's family members were accompanied daily by a physician and by the psychologist, who facilitated communication processes, performing punctual interventions. When asked, the family accepted to donate the patient's organs. It is noteworthy that death, despite being a constituent of human nature, devastatingly affects family members. The importance of communicative processes is perceived not only at the time of death communication, but throughout the patient's hospitalization period. In the case presented, the bond established between family-psychologist was primordial for the acceptance of organ donation.

Key words: breaking bad news, brain death, organ donation, transplantation

1. Introduction

Organ transplantation is a treatment modality that consists in the replacement of a diseased organ or tissue by a healthy one (Brito & Prieb, 2012; Silveira et al., 2009).

Organ donation is historically linked to the attempt to preserve life. Lamb (2000) indicates that the first indices of organ donation are, intrinsically, related to the early history of mankind. According to the Holy Bible, in the book of Genesis, Eve, the first woman, was created from a rib removed from Adam, the first giver.

The world's first transplant, reported by the literature, was conducted in Ukraine in 1933 to treat a patient with acute renal failure (Gregorini, 2010).

The landmark case of Dr. Christian Bernard in 1967 prompted medical-legal debate and discussion about the determination of the death of an organ donor. In 1967, Dr. Bernard transplanted the heart of Denise Ann Darvall, a young woman who had died in a traffic accident, to Louis Washkansky. Louis accepted the risk of surgery, unprecedented in the world, for the certainty that he would not survive, because he was diabetic and had serious liver problems. So, the surgery started when Denise's heart stopped beating. Eighteen days after surgery, Louis

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died. This case prompted debates mainly on the criteria for determining the donor's death and questions related to rejection and probabilities of survival of the receiver (Leite, 2000; Lamb, 2000).

2. The Fear of Death

It was Hippocrates, in 500 BC, who first defined the signs of death in a human being. He described the facial changes in the immediate post-death period, which became known as “*facies hipocratica*”. Among the Greeks, death was determined by cardiac arrest. Yet, in the Judeo-Christian tradition, death was stipulated by a non-functioning lung. The person was dead when he breathed his last breath (Leite, 2000).

Monteiro, Reis, Quintana and Mendes (2015), for example, analyzed the change in death's experience over time. At first, in the Middle Ages, death was a “public and organized ceremony” (p. 548). Although in this period death was experienced with familiarity, men sought to keep distance from the dead, fearing their proximity. This can be perceived by the places destined to the graves, in this period: near churches, what would configure the protection of the saints (Kovács, 1992).

Until the fourteenth century, death was almost exclusively domain of priests, who were the responsible professionals for monitoring the dying ones, helping them to die. At this moment, death was perceived as a God's desire and, once announced, could not be prevented.

Between the fourteenth and fifteenth centuries, Kovács (1992) argues that main fear of man was related to what would come after death, a condemnation, a punishment. Already on this date, “the dead body becomes hidden, because it is unbearable for the eyes” (p. 33).

In this perspective, embalming was the procedure used to preserve the image of the living body, an attempt to deny death. Ahead, in the seventeenth and eighteenth centuries, the fear of being buried alive brings the age of confusion between life and death. Death would only become real once the body decomposition began (Kovács, 1992).

The emergence of spiritism, in the nineteenth century, returns to death a romanticized vision. Now, it is considered as sublime resting, the return to those departed loved ones. The characteristic fear of this phase is with the “other world” souls, who may come to provoke the living. All sorts of rituals were created to ward off these frightening beings (Kovács, 1992).

From the middle of the twentieth century, death came to be perceived as an “uncontestable and unacceptable taboo, unthoughtful and meaningless” (Monteiro et al., 2015, p. 549).

For Kovács (1992), the “shameful death”, is considered a failure. “The triumph of medicalization is, precisely, to keep disease and death in ignorance and silence” (p. 38). Today, in Western society, death is a subject that tends to be denied and/or excluded. There still prevails a kind of idealization, or erroneous belief, that it could be avoided (Pereira, 2005; Sleeman, 2013). A consequence of this perception can be observed in our society by the general difficulty of addressing the issue of “death”, whether in interpersonal, family and/or professional contexts (Monteiro et al., 2015).

One of the greatest difficulties in dealing with the death subject is precisely related to healthcare contexts. According to Pereira (2005), the scientific advances in healthcare are associated with an increase in life expectancy and the general idea of a possible gradual deferral of death.

Consequently, the task of communicating bad news (for example, of transmitting information about the death of an individual to relatives) ends up putting the health professional in contradiction to the healing paradigm; that

is taught during most of the formal education of healthcare professional experiences.

Healthcare professionals, trained to use all the resources available to overcome illness and, consequently, death, tend to view it as a failure (Pereira, 2005; Sleeman, 2013; Monteiro et al., 2015). Monteiro et al. (2015) pointed out that physicians, instilled with the desire to diagnose, prolong life and heal, end up experiencing great anguish when confronted with the (unavoidable) death of a patient.

This condition makes it difficult to create spaces for discussion about the donation of post-mortem organs, since it is related, first and intimately, to the death, and consequent perception of loss, of a person (Quintana & Arpini, 2009). Following is the concept of Brain Death (BD) and its implications for the performance of organ and tissue transplants.

3. The Concept of Brain Death (DB)

In the case of post-mortem donation, the first condition is confirmation of the diagnosis of Brain Death (BD).

The evolution of the concept of BD has its origins in the year 1959; when, in France, such a clinical condition was described by French neurosurgeons as “death of the central nervous system” (Santos, Moraes & Massarollo, 2012).

Also, in 1959, Mollaret and Goulon performed a study with 23 patients in coma and without response to painful stimuli, without brain stem reflexes and with isoelectric electroencephalogram and called this clinical condition by “coma dépassé” (old terminology for the current BD condition) (Santos, Moraes & Massarollo, 2012).

It was in the late 1960s, with the advancement of life support techniques that a new definition of BD was imperative. In 1968, the Committee of the Harvard Medical School in the United States of America defined the irreversible coma as a condition for BD. In 1976, the Conference of Medical Royal Colleges, in the United Kingdom, introduced the use of complementary tests, besides the electroencephalogram, for the diagnosis of brain death. At this time, for the first time, BD was considered equivalent to human death (Santos, Moraes & Massarollo, 2012).

Death could then be defined from the suppression of brain functions (Slade & Lovasik, 2002; Pearson, Robertson-Malt, Walsh, & Fitzgerald, 2001; Sadala, Lorençon, Cercal & Schelp, 2006), expressing total bankruptcy of the entire brain, including the brainstem (Silveira et al., 2009).

The concept of BD, according to Resolution No. 1,480 of the Federal Medical Council (CFM, 1997), must be certified: “considering that total and irreversible cessation of brain functions is equivalent to death”.

In Brazil, the diagnosis of BD is based on clinical and complementary exams; which must record, unequivocally, the absence of cerebral electrical activity or absence of cerebral metabolic activity or the absence of blood perfusion.

The legislation in force in Brazil since 2001 provides that post-mortem donation should be performed by authorization of close relatives (Brazil, 2001).

Since the legislation in force in Brazil since 2001 determines that the family decides on organ donation, in the case of a cadaver donor, it is essential that the population understands the diagnosis of BD, since this is the legal condition for organ donation — and consequently, this could lead to an increase in the number of donations (Teixeira, Gonçalves & Silva, 2012; Silveira et al., 2009).

The concept of BD, intrinsically related to the issue of organ and tissue donation, is still poorly understood

for a large part of the population (Silveira et al., 2009). The little knowledge about BD is considered one of several factors for the refusal of organ donation among relatives of patients in BD condition, as well as religious motivations and the first insufficiently satisfactory contact between the healthcare professional team and the family (Teixeira, Gonçalves & Silva, 2012).

Teixeira, Gonçalves and Silva (2012), in a study, interviewed 136 patients; and observed that only 19.9% believed that the patient in BD condition was, in fact, dead. In addition, 85.3% of the interviewees believed that the physician could make mistakes in the diagnosis of BD and the patient would still be alive. Only 18.4% of the participants reported full reliance on medical diagnosis.

In another study, with a sample of a city in the southern region of Brazil, it was observed that the representation that the interviewees made of BD was a boundary zone that would divide life and death. In other words, the person was already condemned to die, however, would still be alive (Quintana & Arpini, 2009).

It is the difficulty, by the family, of understanding the concept of BD the main cause of non-organ donation. “Those involved cannot understand that a body that has heartbeats, breathing (under equipment control) and sometimes still has temperature, is dead” (Pessoa, Schirmer & Roza, 2013, p. 327; Kocaay, Celik, Ekter, Akyol & Tuzuner, 2015; Ríos et al., 2007; Kim, Fisher & Elliot, 2005; Martínez-Alarcón et al., 2009; Lee, 2011; Ronayne, 2008; White, 2003). In short, “the patient in ME does not look like the way we imagine a dead person” (Powell, 2014, p. 265; Pearson et al., 2001; Sadala et al., 2006).

4. Health Communication

Communication is a process that involves the sharing of messages, both verbal and non-verbal.

In Health Communication, an effective process reduces uncertainties, fears and is a fundamental aid in the acceptance of the disease and active participation in the whole process of caring (Pereira, 2005, p.35).

Communication in the field of health is intended to stimulate reflection and awareness, with the consequent greater empowerment and emancipation, individual or collective of all involved. The strong feature of communication is to provide health education (Ferraz, Silva, Silva, Reibnitz & Backes, 2005; Moreira, Nóbrega & Silva, 2003; Queiroz, Dantas, Ramos & Joge, 2008; Salles & Castro, 2009; Coriolano-Marinus et al., 2014b).

Recently, in the perspective of an emancipatory health education, there is a tendency for the health professional to approach the client (a person) to identify their general and specific needs and then guide them towards designed, intentional choices.

Thus, in the last years, the assumptions of emancipatory health education began to be related to a more dynamic and reflexive communication, with the premise that the simple transmission of information did not ensure significant behavioural changes between professionals and patients (Queiroz et al., 2008).

In agreement with Coriolano-Marinus et al. (2014) and knowing that communication is an indispensable tool of healthcare professionals practice, Ferraz et al. (2005) emphasized that healthcare professionals and patients should be attentive to the transformative capacity of health education and cannot conceive of common-sense knowledge as inferior and easily overcome by knowledge of science. Knowledge of common sense cannot be discarded, but rather must be perfected and/or adapted to scientific knowledge. In this way, they emphasized that health education must guarantee four pillars of learning: (a) learning to know the context of life of the population; (b) learning to act, in a sustainable way, on the context; (c) learning to live with different people; and (d) learning to be, besides exchanging information, with critical transformation and democratization of empowerment.

Specifically, in the context of BD and organ donation, it is important for the healthcare professional to explore the family life context, belief system about the world, the context in which death occurred, and the meaning that family members make of dying process. In addition, it may be prudent for the professional who communicates a BD to respect the philosophical contents and values that the family addresses at the moment of communication, seeking to clarify unrealistic beliefs (for example, that the patient is alive — a common perception of the laity when they see the body maintained by external devices). It is conceived that this communication, based on effective strategies, allows family members to have access to the content communicated in a comprehensible way, allowing the decision to donate or not the organs to be made in a conscious way, allowing an outcome of normal mourning.

5. The ICUs Professionals and the Family

It is understood that the Intensive Care Units (ICUs) are units specialized in the care of critically ill patients who require high complexity support. In addition to the technological support used in these Units, it is essential to emphasize the improvement of human resources (Garanhani, Martins, Robazzi & Gotelipe, 2008; Vicensi, 2016).

Coronetti, Nascimento, Barra and Martins (2006) emphasized that the ICU is perceived by the healthcare team as one of the most tense and traumatizing hospital environments. Part of this perception is due to the constant contact with death and the suffering of relatives.

Vicensi (2016) emphasized that it is in the ICU that the process of dying and its implications are evidenced; since in this context death is a daily situation.

In addition to the professionals involved in this context, it is also worth mentioning the experience of the family that faces the ICU during the hospitalization of a relative. In contact with the imminence of death, the family often does not understand what is happening to their relative; feelings of fear and helplessness arise (Monteiro, Magalhães & Machado, 2017). In this way, caring for family members is an important part of the overall care of inpatients in these Units.

According to the Brazilian Intensive Care Medicine Association (AMIB), humanizing the ICU means caring for the patient globally, considering their socio-familial context (Monteiro, Magalhães & Machado, 2017).

6. Methodology

Using a participant observation, a case study was carried out in an Intensive Care Unit (ICU) of a public hospital of the Health State Department of the Distrito Federal (SES / DF) in Brasília, Brazil.

The choice of case study methodology was given by this being a structured research method, applicable in several contexts, in order to understand contemporary phenomena within realities in which the distinction between phenomenon and context becomes limitrophe (Andrade, Ruoff, Piccoli, Schmitt, Ferreira & Xavier, 2017). In proposing a case study, the researcher proposes to evaluate variables that occur during the process (Serralta, Nunes & Eizirik, 2011).

In the research presented here, the researcher analyzes the process of psychoeducational intervention.

7. Case Report: Findings and Discussion

7.1 Findings

J., 43, was admitted to the ICU after being found unconscious, drunk, on public roads. During a few days of hospitalization, and without the patient's clinical improvement, the first signs that the case would progress to brain death appeared. The patient's BD protocol was open to the first clinical signs compatible with the diagnosis (a perceptible coma state, fixed and arrative pupils, apnea, absence of cough reflex).

The family, very present inpatient care, was accompanied by the psychologist responsible for the ICU. Regarding socio-cultural data, it was pointed out that the family was low-income, with low education level. During the process of communication between healthcare professionals-relatives, it was observed that the family showed low understanding of the diagnosis and prognosis of the patient.

During the ICU's hospitalization period, the family members were accompanied daily by an attending physician, whose main objective was to communicate on the medical bulletin; and by the psychologist, who facilitated communication processes of the medical content and performed punctual interventions in the aspects influenced by the patient's illness. These professionals made up the care team.

Breaking bad news began with the information, by the attending physician, that the BD protocol had been initiated. Throughout the diagnostic process, it was possible to evaluate dysfunctional beliefs of family members, such as: believing that BD was a "state" that could be reversed; fear of medical error; and fear that the organs donated there would be used for trafficking. The interventions of the Psychology team took place in order to clarify and expound the meaning of the diagnosis; using language metaphors.

After closing the protocol compatible with BD diagnosis, the organ recruitment team interviewed the family to question the intent of donation. It is worth noting that, in Brazil, the organ recruitment team is composed of professionals who do not act in patient care. In this way, the professionals do not go through the experience of the conflict of interests; however, it is lost due to the absence of a link between professionals and family members.

In the case discussed here, at the time of the interview of the organ recruitment team, the family requested the presence of the psychologist, once they had established a therapeutic bond and identified this professional as a reference. During this approach, the recruitment team exposed the concept of BD, and questioned the family's intent to accept the donation. The interview ended with the acceptance, by the family members, of organ donation.

7.2 Discussion

The case discussed here highlights the stressful factor that is the work in ICU, as supported by the literature (Garanhani et al., 2008; Vicensi, 2016; Coronetti et al., 2006). Contact with death — whether from the cessation of cardiorespiratory functions or brain functions — becomes part of the routine of healthcare professionals.

The case presented here allows the reader to access the reality of the majority of patients seen in Brazilians ICUs public health network. The difficulty in accessing information about medical diagnoses — specifically discussed here about the BD diagnosis — creates barriers during the communication between healthcare professionals -family members.

As described in the literature, the surprise dimension is a direct variable to the suffering and anguish felt by families (Monteiro, Magalhães & Machado, 2017). In the case reported, the context in which the patient was found (unconscious on the public road), constituted a stressor for the family, who experienced the period of hospitalization with an evident feeling of helplessness.

It is noteworthy that death, despite being a constituent of human nature, devastatingly affects family members. When it occurs within an ICU, death is crossed by clinical, socio-familial and cultural issues (Monteiro, Magalhães & Machado, 2017).

The healthcare context often reinforces old-fashioned communication molds; where professionals and patients occupy different hierarchical levels (Queiroz et al., 2008; Coriolano-Marinus, 2014). This can culminate in a non-effective communication, where the patient is not considered in the treatment decisions.

The follow-up of the family presented here meant to implicate them in the treatment offered and, later, in the decision to donate the organs or not. This strategy approaches the so-called emancipatory health education (Queiroz et al., 2008), with the assumption that the more dynamic and reflexive communication brings the patient closer to an active posture in the treatment.

As for the dysfunctional beliefs observed in this case, such as believing that BD was a “state” and therefore could be reversed; fear of medical error and fear that donated organs would be used for trafficking are also recorded in the literature (Quintana & Arpini, 2009; Teixeira, Gonçalves & Silva, 2012).

The main reason cited in the literature (Pestana et al., 2013) for refusal to donation was also observed in the case presented. Thus, according to the literature, the main obstacle to effective organ donation is family refusal (Martínez-Alarcón et al., 2009; Zambudio, Martínez-Alarcón, Parrilla & Ramírez, 2009). In Brazil, this factor accounted for 44% of the 2,848 interviews conducted in 2015 (ABTO, 2015). In presenting the main causes of family refusal to organ donation, Pessoa et al. (2013) pointed out the difficulty of understanding the BD diagnosis (21%), followed by aspects of a religious nature (19%), lack of technical competence of the team (19%) and the time-consuming process to return the body (10.2%).

The perception that the family has about the services rendered is another variable conditioning the obtaining of the family consent to the organ donation (Moraes et al., 2014) that touches the technical competence. Authors point out that the services rendered, prior to the diagnosis of BD, have fundamental importance on the decision of the relatives to authorize or not, the organ donation of a loved one. This history permeates the family’s perception about the offered care, as well as the care provided by the healthcare team (Victorino & Ventura, 2017).

The importance of communicative processes is perceived not only at the time of death communication, but throughout the patient’s hospitalization period. If the communication between professionals and family members was effective at an early stage, in order to continually update family members about the therapeutic measures being performed and, in addition, not to instigate false hopes of cure, the perception of not having been taken all measures would be extinguished.

In the case presented, the bond established between family-psychologist, ensured that the steps prior to the BD diagnosis were clarified, minimizing communication noises.

The importance of writing down, in medical records, the reasons reported by the families for the refusal to donation is emphasized, since it is from their knowledge that one can think of strategies to increase family adherence to organ donation for transplantation. Through this registry, and based on data obtained in the literature, is that the professional team can discuss changes in the approach to family members, for example. Or, develop training or develop interview scripts to evaluate the knowledge and motivation of family members to donate organs and tissues for transplantation.

Pestana et al. (2013) observed that the motives presented as fundamental at the moment of refusal to donation, referred by the relatives, are susceptible of intervention and training, raising a potential field for psychological work. Here again, the need for proper records in the medical record is discussed. Once the psychologist, a team

member, has access to the range of reasons for family refusal, he could elaborate proposals for training of colleagues, helping with behavioral and cognitive management techniques to obtain a more effective communication process with family members.

8. Conclusion

It is argued that effective communication empowers the patient and/or family member in the active participation in the therapeutic plan established by the multidisciplinary team. In addition, it is evaluated that the effective formation of the professional health-family bond provides, by itself, therapeutic possibility.

In Brazilian reality, the discussion about death — and consequently — about brain death is still restricted and scarcely accessible to the lay public. In this way, it is necessary that the healthcare team develops communication skills.

In addition, it is concluded that the early intervention of potential donor families may favor a positive attitude toward organ donation for transplantation.

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