



## MORAL DISTRESS EXPERIENCED BY NURSES IN RELATION TO ORGAN DONATION AND TRANSPLANTATION

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### ABSTRACT

With a shortage of organs for transplantation purposes, many ethical issues confront registered nurses, particularly those involved in making difficult allocation and rejection decisions and those who interact with people who are not successful in gaining a needed organ for survival. This is a theoretical paper aimed at justifying the need for research investigations on moral distress in relation to organ donation and transplantation. Given the caring nature of nurses and the widespread impact of the shortage of organs for transplantation purposes, moral distress is likely to be present and growing in both incidence and severity.

**Keywords:** moral distress; organ donation; organ transplantation; nurses.

For many years, registered nurses (RN) have been faced with a multitude of ethical dilemmas associated with the shortage of organs for transplantation purposes (Abouna, 2003). Ethical dilemmas are particularly troubling for RNs who have direct contact with people who suffer from and die of potentially avoidable deaths. More specifically, these healthcare professionals are impacted when caring for persons where the only viable treatment is an organ transplant.

Organ donation and transplantation presents many dilemmas that contribute to the scarcity of available organs for transplantation purposes. The complexity of every patient case is compounded by the diverse age of potential recipients, differences in the illnesses causing organ failure, and often highly variable quality of life among potential organ recipients (Victorino & Ventura, 2016). As RNs attempt to navigate these difficult workplace issues, they may find their personal and professional values compromised. Consequently, they may experience moral distress. Moral distress is defined as the

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painful feelings and/or psychological disequilibrium that occur in situations where the ethically right course of action is known but cannot be acted upon (American Association of Critical-Care Nurses, 2004). It is the result of having to act in a manner contrary to personal and/or professional values (American Association of Critical-Care Nurses, 2004; Epstein & Delgado, 2010; Ferrel, 2006).

Although advances in tissue engineering, xenotransplantation, health education, immunosuppressants, and other developments have contributed to a reduction in the acute need for transplants, organ transplantation remains the standard therapy whenever life will or could end soon because of organ failure (Beattie, Austin, Kelecevic, & Goble, 2010).

Unfortunately, the gap between available organs and the number of people waiting for them is growing. In the United States of America – the country with the highest number of transplants performed in the world - 119,765 people out of their 320 million total citizens are on a wait list for an organ transplant (United Network for Organ Sharing, 2016). In Canada, 1,600 Canadians were added to the organ waitlist last year (Canadian Transplant Society, 2016). In Brazil – the second highest country in transplants performed worldwide - a much more populated country with 200 million citizens as compared to Canada's 36 million, 26,425 new people were placed on the waitlist in the 9-month period of January through September 2016 (Associação Brasileira de Transplante de Órgãos, 2016). Among those recorded as waiting since January 2016, 1,509 have died while waiting for an organ transplant (Associação Brasileira de Transplante de Órgãos, 2016). Currently, 32,712 people in Brazil are waiting for an organ transplant (Associação Brasileira de Transplante de Órgãos, 2016). With similar large wait lists in other countries, many RNs around the world will be touched by the ethical dilemmas and moral distress associated with organ transplantation. It is of considerable concern that no research studies aimed at investigating moral distress in relation to organ donation and transplantation could be located. The increasing number of organ transplants performed worldwide and their concomitant moral distress supports the need for research into this phenomenon

## **Background**

The scientific, healthcare, and social evolution that occurred over much of the last century has made healthcare decisions more complex, with ethics an increasingly

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required component of everyday clinical practice (Institute of Medicine, 2007). The ongoing pressure to provide high quality healthcare strategies with good short and long-term outcomes can result in stress, guilt, frustration, anxiety, and other psychological impacts for all involved persons (Epstein & Delgado, 2010; Ferrel, 2006; Oulton, 2006). Healthcare professionals are at risk, and may experience burnout with temporary or permanent job disruption possible.

Most studies to date on moral distress have focused on intensive care units, where the dire nature of each patient's health condition and survival give rise to a range of ethical issues. It is important to extend moral distress research into the area of transplants, so as to determine the extent of moral distress and its impact on the professional wellbeing of healthcare providers.

### **Moral Distress – Definition, Sources, and Consequences**

Work as a healthcare professional is a privilege due the possibility of providing care to people and families in need (Epstein & Street, 2011). However, within this privilege, situations arise in which the provider's preferred ethically-appropriate actions cannot be implemented due to contextual or other constraints (Ferrel, 2006). As noted by Ferrell (2006), these situations have become increasingly frequent and they are likely to continue into the future. Consequently, periodic as well as continuous moral distress is likely to occur.

Although the concept of moral distress has its origins in nursing ethics with nurses recognizing it as a problem for them specifically because of their unique position in the healthcare system, it is now considered impactful on all disciplines that share the responsibility for planning and providing healthcare services including those in leadership roles (Wasylenko, 2013; Austin, 2016). Therefore, it is recognized as a major problem that threatens the integrity not only of affected healthcare providers, but also the healthcare system they work in (Wasylenko, 2013).

As a result, every person involved in transplant organ priority setting and resource allocation should be considered highly vulnerable to moral distress (Austin, 2016; Epstein & Delgado, 2010; Wasylenko, 2013). This is a major concern, as moral distress is a powerful impediment to clinical practice as it engenders feelings of powerlessness, subordination, and inefficiency (Hamric, 2000). It is also concerning as it leads to

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passivity, stasis, and blunted moral sensitivity (Veer, Francke, Strujis, & Willems, 2000). Moral sensitivity arises when a person can recognize the need for decisions in uncertain care situations and have the courage to act appropriately at that time despite impediments to this action (Ahn & Yean, 2014; Lützen, Dahlquist, Eriksson, & Norberg, 2006).

If moral distress remains unresolved and long-standing, then moral sensitivity with subsequent appropriate actions are limited (Veer et al., 2013). It is important to recognize the implications of Andrew Jameton's definition of moral distress as a phenomenon where one knows the right action to be taken, but is constrained from taking it (Jameton, 1984). This situation is different from the classical ethical dilemma where one recognizes that a problem exists with two or more ethically justifiable but opposing actions to be taken. With ethical dilemmas, there are often significant issues or downsides to each potential solution, making it difficult to determine which is the better solution. (Jameton, 1984). Moral distress differs from ethical dilemmas as the ethically correct course of action is not in doubt (American Association of Critical-Care Nurses, 2004). For this reason, Kalvemark, Hoglund, Hansson, Westerholm, and Arnetz (2004) defined moral distress as "traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the healthcare provider feels she/he is not able to preserve all interests and values at stake" (p. 1082-1083). To date, many nurses have been identified and experienced many ethical situations due to the complexity and seriousness of patient care, and also the high potential for futile care, which causes them to experience internal moral conflicts between "what they want to do and what they have to do" (Choe, Kang, & Park, 2015, p. 1690).

Corley (2002) also theorized that moral distress among nurses occurs when the nurse knows what is best for the patient but that course of action conflicts with what is best for the organization, other providers, the patient's family, other patients, and/or society as a whole. Thus, moral distress occurs when the internal environments of nurses, i.e., their values and perceived obligations are incompatible with the prevailing situations and context of their external work environment.

### **From Moral Distress to Moral Residue**

Jameton (1993) was among the first to note that moral distress is a negative emotional and cognitive state in reaction to an event that tends to linger and is therefore harmful, with this type of moral distress termed "reactive distress." Currently, this

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reactive and lingering distress is recognized as a concept that is different from, yet related to, moral distress. It is now considered “moral residue” (Webster & Bayliss, 2000).

In each moral distress situation, the RN has their moral values violated (Webster & Bayliss, 2000). After this, the negative experience of having had to deal with something contrary to their morality continues and will produce moral residue. Moral residue can cause immediate, ongoing, and possibly permanent damage to the individual’s personal and professional life. To explain this relationship, Epstein and Hamric (2009) created a crescendo effect model of interactions between the closely related concepts of moral distress and moral residue.

Epstein and Hamric’s (2009) model of the crescendo effect starts with a clinical issue that causes moral distress, and if repeated or unaddressed over time, this causes a crescendo of moral residue with lingering feelings of distress that continue for months and even years after the morally distressing issue ends (Epstein & Delgado, 2010; Hamric, Borchers & Epstein, 2012). Moreover, according to Epstein and Hamric (2009), there are three potential consequences of moral distress and moral residue. The first consequence is that providers become morally numbed to ethically-challenging situations. As such, they no longer recognize these situations or may simply choose to not engage in situations requiring moral sensitivity. The second consequence is that providers engage in different ways of conscientiously objecting to the trajectory of the situation, such as through workplace bullying or other unhealthy relationships (Catlin et al., 2008). The third and most damaging consequence is burnout, with the person unable to continue working (Meltzer & Huckabay, 2004).

Several studies have already found that moral distress is why some nurses leave or consider leaving their work positions or careers (Corley, 1995; Hamric & Blackhall, 2007). The concern then with moral residue is that it remains and increases over time as a result of repeated episodes of moral distress that are not mitigated or reduced. A breaking point can be reached eventually.

The reason why moral distress and moral residue are concerning then is because of their consequences. Moreover, when moral distress and moral residue are present, they demonstrate the existence of situations that need to be addressed to prevent moral distress and moral residue. In the case of organ shortages, ethical and practical actions must be taken to increase the number of organs available for transplantation purposes. If not, the

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practical and ethical or moral impacts of a growing shortage of organs will be increasingly severe over time. With little to no recognition of moral distress, and none or inadequate action to address moral distress, moral residue could grow among RNs (Epstein & Delgado, 2010).

Not only is theorizing important about moral distress in relation to organ donation and transplantation, but research studies are needed in order to understand and address this type of moral distress. A search of all 271 databases listed in the new EBSCO Discovery Service which covers most library databases was conducted for published research articles on this topic using the search terms: moral distress AND organ donation AND research. This search resulted in only 10 potential articles. Of these, nine were published in academic journals, with two being duplicates and one a journal supplement. Consequently, only six research articles were identified as potentially relevant for this review and each carefully read (Bjork & Naden, 2008; Elpern, Covert, & Kleinpell, 2005; Haimes & Taylor, 2011; Ledger, Begley, Reid, Prior, McAuley, & Blackwood, 2013; Mandell et al., 2006; Squee, Payne & Vlachonikolis, 2000). None of the studies were aimed at analyzing, understanding, identifying, and/or discussing the relationship between moral distress and organ donation or organ transplantation.

However, one of the six studies were notable as it assessed the level of moral distress among nurses working in a US medical intensive care unit (ICU) (Elpern, Covert, & Kleinpell, 2005). More specifically, it identified situations that result in high levels of moral distress, explored the implications of moral distress, and determined associations between moral distress and select nurse characteristics (Elpern, Covert, & Kleinpell, 2005). This study revealed a high level of moral distress among these nurses, as illustrated by their unwillingness to donate blood or sign up as organ donors. This unwillingness was present despite a clear scarcity of blood products and organs for transplantation; a critical disparity between demand and available resources. These ICU nurses frequently cited their distress at seeing blood products and organs “squandered” on patients who would not or could not benefit from them (Elpern, Covert, & Kleinpell, 2005). For instance, one of the nurses asked that their name be removed from an organ donor list after having been placed there because she felt scarce organs were not used properly. Another indicated feeling ashamed over thinking about not being an organ donor as she cited cases of liver transplants among patients despite recent alcohol use and when a second transplanted organ was provided despite ongoing drug or alcohol abuse even after the first organ graft failure (Elpern, Covert, & Kleinpell, 2005). These nurses

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clearly demonstrate moral distress. The moral distress identified in this study arose in relation to what was considered the inappropriate use of blood and organs.

## **Organ Donation and Transplantation**

Although one could argue that all nurses can experience moral distress, Rice, Rady, Hamric, Verheijde, and Pendergast (2008) believes nurses who care for transplant patients experience more moral distress than other nurses do. There are no studies to validate or disprove this belief. Research is needed now to identify, understand, and address moral distress among RNs, not only because it is believed to be common now and expected to increase in the future. This research is especially imperative in light of aging populations and rising chronic illness rates in all developed and many developing countries.

Arguably, the greatest ethical healthcare dilemma now in modern societies is that organ rationing is required because of a shortage of available organs for transplantation. For RNs, it is necessary to decide among ill, suffering, and at times dying patients, to determine which one will obtain each available organ. This decision-making process will evoke feelings, ranging from mild to extreme, including the fear of making the wrong choice, unhappiness over the fact that many other patients will continue to suffer and die, and guilt as their professional values of caring for all patients equitably cannot be met. These considerations illustrate Jameton's (1993) definition of moral distress, where one knows the right action to be taken but is constrained from taking it.

Organ donation and transplantation present unique clinical practice considerations, as it is essentially the process of taking an organ from one person and giving that organ or part of the organ to another person (United Network for Organ Sharing, 2016). This process typically begins with the death of the donor, due either to cardiorespiratory arrest or brain death. As such, it is by its very nature an emotionally stressful event, both for the family and all involved healthcare professionals. During this process, nurses will likely care for the proposed recipient as well as any patients who do not get an organ transplant. Nurses will also care for the organ donor, such as through monitoring and maintaining their vital signs so organ extraction can be successful (Monforte-Royo & Roque, 2012).



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It is not surprising then that a study by Wiegand and Funk (2012), aimed at identifying clinical situations that cause critical care nurses to experience moral distress, found moral distress was most often related to end-of-life matters (73%), including organ donation (11%) (Wiegand & Funk, 2012). As such, this study demonstrated that moral distress can occur among all nurses working in intensive care units and potentially any nurses involved in any stage of the organ donation-transplantation process. Research is needed to identify the incidence and prevalence of moral distress in relation to organ donation and transplantation. Moreover, research is needed to determine its consequences, not only because it is important to know this, but for the development of actions to reduce or prevent moral distress and spare nurses from it. Moreover, patients and families will benefit from this research, as ways are found to address their needs as well.

## Conclusion

This paper highlights the fact that research attention has not focused on the moral distress of RNs in relation to organ donation and transplantation. To date, no studies have been done to help understand, address, or prevent moral distress, yet this specific form of moral distress is worldwide and growing in incidence and severity. Nurses are unique among all healthcare professionals as they more typically have a close up and personal relationship with patients and their families. As such, nursing evidence is needed for effective amelioration and prevention efforts. These efforts will follow if moral distress is recognized as a risk arising from the responsibility placed on nurses and others to work in all ethically-challenging situations associated with organ donation and transplantation. Not only will nurses benefit if ways are found to prevent and address moral distress, but patients and healthcare systems will benefit, through becoming more moral communities (Austin, 2016).

This research is imperative as the need for transplants is growing as a result of more end-stage organ failure (Scheuber, 2016). There has always been a need to find some sort of balance between doing good and at the same time doing no harm – *primun non nocere* (Begley & Piggott, 2012). It is time to create evidence-based insight and strategies that allow nurses and other healthcare professionals to discharge their important work without moral distress and moral residue.



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### **Conflict of Interest**

The authors declare that there is no conflict of interests regarding this paper.

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