

Empirical Research on Moral Distress: Issues, Challenges, and Opportunities

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Abstract Studying a concept as complex as moral distress is an ongoing challenge for those engaged in empirical ethics research. Qualitative studies of nurses have illuminated the experience of moral distress and widened the contours of the concept, particularly in the area of root causes. This work has led to the current understanding that moral distress can arise from clinical situations, factors internal to the individual professional, and factors present in unit cultures, the institution, and the larger health care environment. Corley et al. (2001) was the first to publish a quantitative measure of moral distress, and her scale has been adapted for use by others, including studies of other disciplines (Hamric and Blackhall 2007; Schwenzer and Wang 2006). Other scholars have proposed variations on Jameton's core definition (Sporrong et al. 2006, 2007), developing measures for related concepts such as moral sensitivity (Lutzen et al. 2006), ethics stress (Raines 2000), and stress of conscience (Glasberg et al. 2006). The lack of consistency and consensus on the definition of moral distress considerably complicates efforts to study it. Increased attention by researchers in disciplines other than nursing has taken different forms, some problematic. Cultural differences in the role of the nurse and understanding of actions that represent threats to moral integrity also challenge efforts to build a cohesive research-based understanding of the concept. In this paper, research efforts to date are reviewed. The importance of capturing root causes of moral distress in instruments, particularly those at unit and system levels, to allow for interventions to be appropriately targeted is highlighted. In addition, the issue of studying moral distress and interaction over time with moral residue is discussed. Promising recent work is described along with the potential these approaches open for research that can lead to interventions to decrease moral distress. Finally, opportunities for future

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research and study are identified, and recommendations for moving the research agenda forward are offered.

Keywords Moral distress · Empirical research · Moral residue · Moral distress scale · Moral distress thermometer

There has been an explosion of interest in moral distress in the last decade, both within nursing and in other disciplines. A recent keyword search of the concept in PubMed revealed over 400 citations. A significant part of this interest is the growing body of empirical research on moral distress. Although the concept was first defined in the US over 25 years ago by Jameton (1984), alternative definitions and concepts abound and there is no central agreement on the key definitional features of the phenomenon (see Lutzen's paper, this issue). While such variation is commonplace when concepts are initially explored, this variability greatly complicates building a coherent body of knowledge (see Pauly et al. this issue). In addition, moral distress is increasingly being studied around the globe, which introduces cultural differences and variability due to different understandings of professional roles. As a consequence of these factors, research is in its beginning stages and what is known about moral distress has emerged primarily from small descriptive research studies using quantitative and qualitative methods of inquiry. Studies using quantitative methods such as Corley's work and related research using the Moral Distress Scale (MDS) are predominant examples. Many of these studies have been narrowly focused on one or two groups, such as medical students (Wiggleton et al. 2010) or neonatal intensive care unit (NICU) nurses (Cavaliere et al. 2010). There are only three intervention studies (Beumer 2008; Rogers et al. 2008; Sporrang et al. 2007) at present, each employing educational interventions to address moral distress. Although many ideas have been advanced to address moral distress in clinical settings, these have yet to be systematically studied.

This article explores empirical research done to date with a focus on the challenges and opportunities related to studying moral distress. Three approaches to measuring moral distress, including the author's work on developing a revised MDS usable by multiple disciplines and in varied settings, are described. Recommendations for moving research in the field forward are offered.

Qualitative Studies of Moral Distress

Most studies of moral distress have been descriptive, consisting of interviews or focus groups and conducted primarily with nurse participants. Interestingly, many of these studies did not start out to study moral distress, but the findings were so strongly descriptive of the phenomenon that they helped delineate the contours of the concept (see for example Pike 1991; Gordon and Hamric 2006; Harrowing and Mill 2010). One Canadian group with a research focus on ethical practice and the ability of nurses to practice with moral agency highlighted the difficulties nurses

experience in attempting to enact ethical practice (see Rodney et al. 2002; Varcoe et al. 2004). Data from these various studies helped illuminate the experience of moral distress, including symptoms and sequelae seen in responses to the experience. Symptoms reported include frustration, anger, guilt, anxiety, a sense of powerlessness, and even physical symptoms (Wilkinson 1987/1988; Gutierrez 2005; Epstein and Hamric 2009; Corley 1995; Pike 1991; Erlen and Frost 1991). Some qualitative studies have focused explicitly on moral distress (see, for example, Austin et al. 2003; Ferrell 2006; Brazil et al. 2010).

These and other studies have identified root causes of moral distress that extend beyond the institutional constraints and power hierarchies that Jameton focused on in his initial definition (1984). Additional factors such as feelings of powerlessness or lack of knowledge, clinical situations such as those involving aggressive treatment to terminal patients or inadequate informed consent, and external factors in the situation or institution have been identified as additional sources of moral distress in multiple studies (Elpern et al. 2005; Gutierrez 2005; Hefferman and Heilig 1999; Kalvemark et al. 2004; Ferrell 2006). Examples of root causes identified from qualitative studies can be seen in Table 1. Generally, these various root causes have not been explicitly explored with regard to the interconnections between individual, unit/team, and system factors; some efforts in this direction have been made. For example, Hamric and Blackhall (2007) explored the relationships among nurse and physician moral distress with these providers' perceptions of collaboration, ethical climate, and quality of care.

Some studies also noted the powerful lingering effects of moral distress, named variously as “reactive moral distress” by Jameton (1993) and later as “moral residue” by Webster and Bayliss (2000). In a recent study, Epstein and Hamric (2009) reported qualitative data from interviews with nurses and physicians that linked recurrent experiences of moral distress, often due to ongoing unit cultural and system factors such as poor team communication or lack of administrative support, with increasing moral residue over time in a model they named “the Crescendo Effect” (see Fig. 1). This model posits that crescendos of moral distress and moral

Table 1 Examples of root causes of moral distress

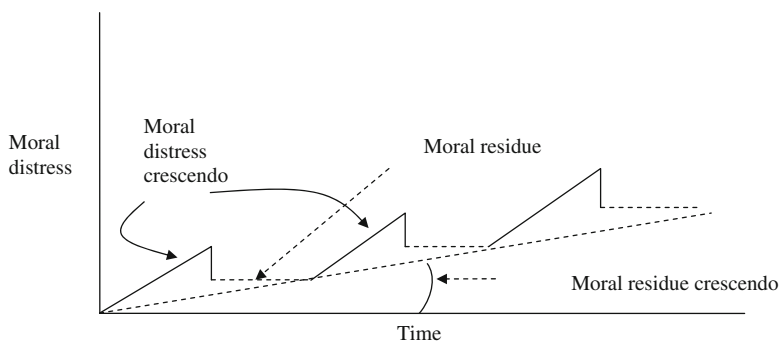
Factors internal to the caregiver
Perceived powerlessness
Lack of knowledge of alternatives, or the full situation
External factors in the situation
Institutional constraints such as inadequate staffing
Lack of administrative support
Incompetent caregivers
Clinical situations
Unnecessary/futile treatment
Aggressive treatment not in the patient's best interest
Inadequate informed consent
Lack of truth-telling, such as giving false hope

residue build up over time in units and systems where moral distress is unaddressed. Such crescendos can erode care providers' moral integrity, resulting in desensitization to the moral aspects of care. This desensitization can in turn lead to withdrawal from troubling cases, conscientious objection, or leaving a position and/or profession. While this model has yet to be directly tested, its elements are visible in earlier literature even if not named in these terms (see, for example, Fry et al. 2002).

Currently, qualitative studies of moral distress continue to be important as exploration of the phenomenon extends to other disciplines and other cultures. Work to date makes clear the importance of context and the clinical environment to the experience of moral distress—for example, Gordon and Hamric (2006) identified political and sociocultural contexts that represented potent barriers to nurses seeking to access ethics consultation for their patients. These barriers resulted in nurses not acting on their judgment that ethics consultation was needed, and experiencing moral distress as a consequence of inaction. Qualitative methods allow for more in-depth exploration of contextual dimensions of practice, and give a sense of temporal sequencing in the rich narratives of research participants.

Three major issues stand out when reviewing qualitative research to date on moral distress. First, differing understandings of moral distress and the differing terminology that have emerged from various qualitative studies complicate attempts to generalize findings from this work. While it is the nature of qualitative work to explore phenomena without a priori definitions and generalizability is not a goal, analyses using different definitions of moral distress or related but different concepts cannot be aggregated to form a more robust understanding. In addition, many studies have very small and targeted respondent groups, primarily in nursing. As a result, the existing knowledge base is fragmented in some important respects.

Second, in many studies the concept has emerged during data analysis as a powerful, even dominant theme in the narrative data rather than being the focus of the study itself. For example, Gordon and Hamric's (2006) study of nurses' willingness to call for an ethics consultation showed that moral distress was a dominant feature in situations where nurses wanted to call for a consultation, but felt



Note: solid lines indicate moral distress, dotted lines indicate moral residue

Fig. 1 Model of the Crescendo Effect (used with permission)

they could not act on that judgment because of conflict in the situation. Epstein's (2008) qualitative study of NICU nurse and physician perspectives on caring for newborns for whom a decision was made to withdraw treatment resulted in data that led to identification of the Crescendo Effect (Epstein and Hamric 2009). As a result, much of what is known about moral distress has been learned indirectly, rather than through a clear focus on studying the phenomenon directly. This has further fragmented the knowledge base.

Finally, most studies have reported factors that thwart nurses' moral agency and damage their integrity (one notable exception being the work of Rodney and colleagues on identifying a desirable "moral horizon"; Rodney et al. 2002). This emphasis is understandable since nurse participants in studies were most frequently asked to discuss ethical problems or tensions in their practices. However, much less is known about factors that protect moral integrity and mitigate the effects of moral distress. One recent example of research in a positive direction is the work of Harrowing and Mill (2010) in their study of Ugandan nurses. Moral distress assumed some different dimensions in this low-income and resource-constrained country. The authors noted the positive attitudes and resilience demonstrated by Ugandan nurse participants involved in an educational program, and their ability to protect their integrity despite the challenges of the context in which they provided care. This study demonstrates as well the importance of culturally-specific and sensitive research.

Quantitative Studies of Moral Distress

As moral distress has been increasingly recognized as a factor in nurses choosing to leave nursing, interest has increased in finding ways to measure moral distress. Quantitative research methods become important when one wishes to explore multiple variables in relationship using large samples. This methodology is also necessary for intervention research, as outcomes reflecting changes due to the intervention require comparison using reliable and valid measures. One study tested an educational intervention but found no change in moral distress; among other considerations, the authors questioned the instrument as a possible reason for the lack of measurable change (Sporrong et al. 2007).

Mary Corley developed the first and most widely-used US measure, the MDS. Published in 2001 (Corley et al. 2001) and designed for use with critical care nurses, the measure was developed and tested in the 1990s. Using Jameton's definition of moral distress (1984; 1993), role and values theories, she constructed a 38-item scale that measures the frequency and intensity of distress experienced in a variety of clinical situations. This measure has been adapted for use by others, including a study of Canadian registered nurses (Pauly et al. 2009) and studies of other disciplines (Hamric and Blackhall 2007 [physicians]; Schwenzer and Wang 2006 [respiratory therapists]). Advantages of the MDS include the ability to examine the dual dimensions of frequency of moral distress-inducing situations and the intensity of the distress experienced. Corley has encouraged modification and continued testing to improve the instrument. Challenges in using the MDS include its length, its nursing focus, and that some items do not reflect current practice. Corley is no

longer recommending its use (personal communication, 2011) as a substantive revision has been developed (see below). The revised instrument is cumulative so that it captures both moral distress and moral residue—a separate measure of moral residue has yet to be developed.

Other scholars have proposed variations on Jameton's core definition and as a result use different measures (Sporrong et al. 2006, 2007) or developed measures for related concepts, such as moral sensitivity (Lutzen et al. 2006), ethics stress (Raines 2000; Ulrich et al. 2007), and stress of conscience (Glasberg et al. 2006) [see Lutzen, this issue]. Still others have developed measures specific to studying a particular population, such as medical students (Wiggleton et al. 2010) or nurses in Israel (Eizenberg et al. 2009).

Similar to that of qualitative studies, this problem of different definitions compounds the difficulty of developing adequate measures, since how a concept is defined matters greatly in measurement. Valid measures require a tight linkage between the concept and the items developed for the measure. It is clear that, at present, multiple measures exist which measure different concepts. While this state of affairs is understandable in the early stages of defining a complex concept, researchers need to be clear that they are measuring different aspects of a complex domain, or different concepts altogether.

Further challenges in evaluating quantitative studies include methodological problems. Many studies have small sample sizes from single sites; in some studies, respondents come from varied disciplines but the findings are lumped together without an indication of whether there are discipline-specific differences. Other studies employ measures with questionable psychometric properties: some scales have very few items to capture such a complex concept while others have too many items to allow for inclusion of measures of other variables; and, some reports show scant attention to the rules of psychometric testing or factor analysis. Journal reports often do not provide enough detail on the instruments employed to gather study data to enable readers to have confidence in the process used for instrument development (in the case of new instruments) or justification for the validity of existing instruments.

All of these challenges point to the need for consistency in terminology when defining moral distress and for rigorous instrument development procedures that test whether the measure is accurately measuring the underlying construct. It is possible that these early and differing instruments are measuring aspects of varied concepts, related or only quasi-related to moral distress. While the field will undoubtedly need multiple instruments, underlying conceptualizations must be clear in order to evaluate the results of any study. Rigor in testing psychometric properties and transparency in reporting the results of this testing is necessary to evaluate the trustworthiness of research findings—this is true in any study using quantitative measures, but is especially the case when attempting to measure such a complex construct as moral distress.

Recent Approaches to Instrument Development

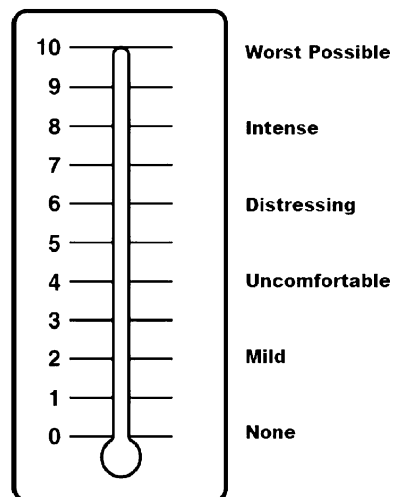
Caution must also be exercised when translating findings from one culture to other systems and cultures, as the international research is quite varied in its approach to

studying this phenomenon. Eizenberg et al. (2009) reported the development and testing of a culturally-specific instrument to measure moral distress in Israeli nurses. They started with qualitative interviews to elicit culturally-specific themes, then utilized those themes to design a 15-item quantitative measure. This is a promising approach to identify the unique aspects of professional practice in different cultures that could give rise to moral distress.

Wocial (in press; Fig. 2) has developed a “moral distress thermometer” for use in clinical practice settings. Providers are asked to rate their current (within the past week) level of moral distress and the reasons for this rating, rather than attempt to measure cumulative levels over time. The “thermometer” is basically a visual analogue scale that is quick and easy to complete. Wocial also plans to include check boxes listing various root causes so that participants can indicate which are contributing to their level of distress. Developed for diagnostic purposes in clinical situations and ethics consultations, it has demonstrated convergent validity with Corley’s original MDS in early testing (personal communication, 2011). The ability to measure real-time moral distress and identify root causes present in the clinical environment opens an exciting avenue for research that can target interventions to address moral distress.

The author has worked with colleagues to revise Corley’s MDS in an effort to improve the measure’s ability to detect a variety of root causes and to develop a shortened form of the instrument more suitable for multivariate research and clinical use (Hamric et al. 2012). The new instrument, the Moral Distress Scale-Revised (MDS-R), was developed with careful attention to content and construct validity testing. It has 21 items; numerous changes have been designed to reflect more of the root causes of moral distress and to broaden the scale’s applicability to a variety of settings and providers. The MDS-R can yield an overall score representing a respondent’s level of moral distress that can be used in other analyses. There are six versions for physician, nurse, and other healthcare professionals in both pediatric and adult settings. Initial reliability and validity testing shows promise. Because root

Fig. 2 Wocial’s moral distress thermometer (used with permission)



causes may hold the key to targeting interventions that can ameliorate moral distress, the instrument has been designed to identify the root causes operating in various settings.

Opportunities in Continuing Research on Moral Distress

Both qualitative and quantitative methods are important in the continuing research into moral distress and moral residue as differing approaches are important in studying complex phenomena. Qualitative work gives a sense of the contours of the concept, and locates moral distress in the specific context within which it occurs. As such, it sensitizes us to a more complete and nuanced understanding of moral distress. One can argue that the initial qualitative studies with their powerful narratives of nurses experiencing moral distress helped promote sustained research interest in the phenomenon. Although some authors have questioned the ability of quantitative measures to adequately capture a phenomenon of such complexity (Austin et al. 2005), quantitative measures of moral distress are also necessary. These instruments are particularly important as research efforts move into studying interventions. These studies require stable and sensitive measures in order to determine whether an intervention has been effective in decreasing moral distress. Ongoing research should use both approaches, using mixed methods (Creswell 2009) to more adequately capture the dimensions of the concept, but such methods are complex and funding has not always been forthcoming to support such research.

There are many opportunities for future research in an area as young and evolving as is empirical ethics, particularly research on moral distress. Over time, research efforts need to move toward the following:

- more multi-site studies, as previous studies reveal that the level of moral distress experienced by care providers is partly a function of the environments in which care occurs (Corley et al. 2005; Hamric and Blackhall 2007; Pauly et al. 2009);
- replication studies that use previously validated instruments rather than studies that create new instruments for one-time use (while still in the pilot testing stage, the Moral Distress Thermometer and the MDS-R are two possible instruments that can be used in replication studies);
- more multi-disciplinary studies of a variety of healthcare disciplines. Kalvemark et al. (2004) were among the first to study members of other disciplines; since that time, a number of studies have been conducted of non-nurses. It is clear that moral distress is a phenomenon shared by multiple care providers but more work is needed to understand the differences and similarities between disciplines;
- related to the previous recommendation, clear delineation of findings by type of care provider is necessary, particularly when respondents are from multiple professional disciplines or include non-professional caregiving staff;
- measuring moral distress over time to explore the Crescendo Effect;
- researching interventions that promote moral agency and preserve moral integrity;
- building a cumulative knowledge base of root causes of moral distress and their interrelationships that will support this intervention research;

- studying the effects of care-provider moral distress on patient experiences and outcomes. Qualitative studies have indirectly illuminated effects on patients but only through the eyes of the providers studied (see for example Gutierrez 2005). Direct study of patients' experiences has yet to occur.

The ultimate goal of research programs focused on moral distress is to develop and test interventions that will decrease and/or prevent moral distress. But to know whether we have achieved that goal, we have to have quality measures.

Conclusion

Moral distress differs from other forms of emotional distress (Epstein and Hamric 2009). It is important precisely because it is so powerful and so destructive to the moral agency and integrity of healthcare providers. Experiences of moral distress compromise providers' core values or duties, which are the fundamental ingredients of their moral integrity. Over time, these compromises can have negative and long-lasting effects that can lead healthcare providers to become desensitized to the moral dimensions of their work or even to leave their profession. Numerous studies have demonstrated these connections, and the latter one is a chief reason for the attention being paid to this phenomenon. Compromise in *moral* integrity must be evident in the measures used in moral distress research. There is an urgent need for continued research that, even as we seek to refine and better understand moral distress, moves to identify interventions that decrease moral distress and protect the integrity of healthcare professionals. The negative effects of provider moral distress on patient outcomes have yet to be studied, though they are hinted at in some qualitative studies.

In thinking about why this work matters, an anonymous nurse's eloquent response to a *New York Times* article on moral distress (Chen 2009) makes clear the price healthcare professionals are paying to maintain their moral integrity in the face of moral distress:

I quit nursing last month for exactly this reason [moral distress]. The stress on caring nurses (and doctors) is unbearable. Competent nurses feel frustrated at their own powerlessness, frightened of being sued, and heart-broken about what is being done to patients for all the wrong reasons. Furthermore, the healthcare crisis is so severe that all excellent practitioners worry constantly about mistakes that occur every day simply because of the chaos in the system itself, not because anyone did anything incompetent.... I came to nursing because I care so deeply about patients, but I left it because I want work that doesn't hurt me as a person [Anonymous, reported in Parker-Hope, 2009].

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