


ARTICLE

Moral Distress Under Structural Violence: Clinician Experience in Brazil Caring for Low-Income Families of Children with Severe Disabilities

Ana Carolina Gahyva Sale¹ and Carolyn Smith-Morris^{1,2*} 

¹Department of Anthropology, Southern Methodist University, Dallas, Texas, USA

²University of Texas Southwestern Medical Center, O'Donnell School of Public Health, Dallas, Texas 75390-9096, USA

*Corresponding author. Email: Carolyn.Smith-Morris@UTSouthwestern.edu

Abstract

Rigorous attention has been paid to moral distress among healthcare professionals, largely in high-income settings. More obscure is the presence and impact of moral distress in contexts of chronic poverty and structural violence. Intercultural ethics research and dialogue can help reveal how the long-term presence of morally distressing conditions might influence the moral experience and agency of healthcare providers. This article discusses mixed-methods research at one nongovernmental social support agency and clinic in Rio de Janeiro, Brazil. Chronic levels of moral distress and perceptions of moral harm among clinicians in this setting were both violent, following Nancy Scheper-Hughes' use of that term, and a source of exceptional and innovative care. Rather than glossing over the moral variables of work in such desperate extremes, ethnography in these settings reveals novel skills and strategies for managing moral distress.

Keywords: moral distress; ethnography; structural violence; Brazil; intercultural ethics

Introduction

The fact is that life on the Alto do Cruzeiro resembles nothing so much as a battlefield or an emergency room in a crowded inner-city hospital. Consequently, moral thinking is not guided by the blind justice and commitment to abstract universal principles.... In the shantytown, day-to-day moral thinking is guided by a "lifeboat ethics."^{1,2}

In the context of "everyday violence" where regular, poverty-related abuse and violence are normalized, emotions like distress are shown—and in Scheper-Hughes' ethnography *felt*—differently.³ In such extremes, emotions and corresponding moral expectations and codes are transformed to reflect local, material conditions, and limits. Those local structural factors affect not only what people name as distressful but also how they make sense of these experiences and care for their own well-being.^{4,5}

Although the moral distress present in conditions of chronic extreme poverty has been well described,^{6,7} the moral reactions and coping strategies of healthcare personnel in these circumstances have not received adequate attention. Only recently has research begun to describe and measure clinicians' moral distress in different cultural settings.^{8,9,10} Yet clearly, the vulnerability of health workers in global settings of extreme deprivation and danger is "all too real."¹¹ What happens when the structural circumstances that often cause moral distress are chronic? Does chronic extreme poverty produce apathy and fatigue among healthcare providers, or do unique resiliencies emerge among such professionals?

These questions are relevant to global bioethics and to intercultural dialogue about the diverse value systems in which moral distress might occur.^{12,13} The concept of moral distress as a reaction to ethical dilemmas in healthcare was developed by the bioethicist Andrew Jameton during the early 1980s in the field of nursing¹⁴ and, in different variations, has flourished in the nursing literature and research over the past 20 years.^{15,16} Moral distress is “the queasy, inchoate feeling that arises when you’ve done everything right, but know you’ve done something wrong.”¹⁷ According to Jameton, moral distress develops in a situation when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.¹⁸ But as Carina Fourie and others have recently argued,^{19,20} moral distress can arise from both constraints and from uncertainty, pointing to the larger context in which distressing events have their meaning.

Moral distress is likely to emerge in the context of poverty and structural violence²¹ due to insufficient resources, over-work, and impotence.²² When assessing the moral distress of nurses, technicians, and nursing assistants in Rio Grande do Sul, Grazielle de Lima Dalmolin et al. found “insufficient working conditions” to be one of the most frequent sources of moral distress.²³ However, when creating a moral distress instrument, specifically for the Brazilian context, this “insufficiency” is broad and inherent to the production of “social vulnerability” and “lack of problem solving ability of health actions due to social problems.”²⁴ Chronic “insufficiency” as a factor in the experience of moral distress may, therefore, be common in poor and low-income contexts where “resource shortages” are persistent.²⁵ In such conditions, workers may face long-term moral distress, feelings of helplessness, as well as a “passive acceptance of resource shortages.” Certainly, this chronicity²⁶ of moral distress can be expected to change a person’s emotional experience of moral events, much as Scheper-Hughes’ work among grieving mothers in Brazil showed.²⁷

Variations in moral distress across contexts of chronic structural violence merit further attention. One setting of long-term, inter-generational “insufficiency” of care and structural violence is Rio de Janeiro, Brazil. Once the capital and a major source of revenue since the colonial era, Rio de Janeiro has been in economic crisis for several years. A combination of inflation, corruption investigations of Petrobras, a large Brazilian petroleum company, and public protests led to a crippled social safety net for an already struggling population.²⁸ Brazil’s national health system, the Sistema Único de Saúde, aims to provide free healthcare for all as detailed in the 1988 Constitution.²⁹ Yet, the system continues to struggle alongside the economy.³⁰ In Rio, specifically, there is a frequent lack of state pharmaceutical supplies and a deficiency in specialized physicians.³¹ Non-governmental organizations attempt to fill these structural and care gaps in Rio de Janeiro but are not always successful.

To better understand experiences of moral distress in circumstances of chronic, extreme poverty, we examined the experiences of staff in one Brazilian organization serving families of children with severe and life-threatening disabilities. Our principal interest had been clinicians serving children with congenital Zika syndrome, which was prevalent in Rio, Brazil in 2015–2016. But we soon realized that the limited healthcare resources created potentially stressful circumstances for a broad array of clinicians, not just those focused on Zika. According to the World Health Organization’s definition of congenital anomalies, children with congenital Zika syndrome have life-threatening and debilitating conditions, requiring various forms of treatment and care, including surgery for survival.³² In Rio de Janeiro, the availability of these treatments and services critical to the health and longevity of children with life-threatening and debilitating conditions is, at best, incomplete. Average waiting times for consultations in specialized fields in Rio de Janeiro can range from 30 to 120 days.³³ In addition to these healthcare gaps, care for children with congenital anomalies involves distinctive challenges for decision-making among patients, parents, and providers. Not only is direct care with patients and families more distressing than indirect care,³⁴ but also pediatric treatment decisions are often shared between professionals and parents.³⁵ Clinicians and especially nurses³⁶ can be “caught in the middle,”^{37,38} causing even higher levels of distress.

Using mixed methods, our goal was to measure and understand the experience of moral distress in one Brazilian care setting. In particular, we aimed to discover whether and how clinicians at one nonprofit agency experienced moral distress in their work among under-resourced families of children with life-threatening conditions. Although our sample is not large enough to support broadly generalizable claims, we used a well-established moral distress scale to promote comparison with the published

literature. This tool helped us gather not only perceptions of moral distress, but also helped facilitate narratives about the frequency and intensity of distress, even if such terms were new to our interlocutors. After detailing our methodologies, we discuss three key findings and reflect on the value of further work to understand intercultural variation in the experience of moral distress.

Methods

This mixed-methods study was conducted within the Associação Saúde Criança (hereafter, the “Child Health Association” or simply “Association”), an independent social service organization in Rio de Janeiro, Brazil. The Association has assisted more than 72,000 individuals in overcoming the hardships of post-hospitalization and offering guidance and opportunities for sustainable social change for families to have rights and quality of life guaranteed.³⁹ The Association serves to link and support patient families in obtaining necessary treatments and care through multidisciplinary methodology, fostering their knowledge of public and private institutions.⁴⁰ Clients of the Child Health Association are families living in extreme poverty, earning less than R\$178/month per family member, an income level that makes them eligible for Brazilian financial assistance through Bolsa Família, the Brazilian social welfare program for low-income families.⁴¹ The Association’s approach to services is based on the belief that if families are helped to obtain both material resources and psychological support, they will develop greater self-sufficiency within two years. The agency’s mission is to help families “struggling to fulfil the most basic needs like health, education, and access to water and sanitation”⁴² gain access to existing public services, to increase their own abilities and skills, and know how to better advocate for themselves within Brazil’s fragile and limited social safety net.

Study Design and Participants

An ethnographic design was used to promote the broadest possible perspective on local experience of moral distress.⁴³ Participant observation within the Child Health Association over three months in 2019 involved: a total of 34 interviews with staff, clients, and stakeholders in Portuguese; attendance at approximately 15 staff meetings; observation in more than 50 client encounters and appointments; and volunteering in major areas of the organization including education, psychology, social work, and outreach. After in-depth conversations with both the organization’s head psychologist and the outreach coordinator, modifications to a translated version of Ann Hamric’s instrument to measure moral distress in healthcare professionals were made, including use of local terminologies and removal of inapplicable hospital-specific wording like “bed capacity.”⁴⁴ Through a detailed review of the relevant literature, meetings of the research team, and consultation with bilingual experts within the Association, we also developed an Interview Guide to elicit staff perspectives and descriptions of moral distress. All staff and volunteers with immediate contact and direct work with families were invited to participate.

Data Collection and Analysis

Following an informed consent process with each participant, Ana Carolina Gahyva Sale conducted 19 interviews with clinicians and volunteers at the Association in private offices, in Portuguese. Additionally, she interviewed 15 caregivers of children with severe and life-threatening disabilities to better understand their struggles and context. Semi-structured interview questions addressed: how participants saw Rio de Janeiro as a place for children with chronic illness and severe disabilities to receive healthcare; how they perceived the Child Health Association in this context; any ethical problems that they encountered in their work; the largest ethical problem that they had ever faced and how they coped; and a discussion of any other changes that might assist clients’ and staff’s own well-being. This portion of interviews was recorded, transcribed, and translated for dual-coder analysis. Participants also completed the modified version of the Measuring Moral Distress—Healthcare Professionals (hereafter the “survey”) either electronically or on paper as they preferred.

Results

We first make overall comments about the survey results, then present three themes that reflect the analytical triangulation of survey results, interview narratives, and participant-observational data.

Nineteen staff completed the survey and interviews, including physicians, social workers, and psychologists. Though difficult to evaluate high versus low moral distress using the relatively new moral distress survey instrument, the mean composite score of our sample was 60.8 out of possible total of 432, which is low in comparison to other published studies.⁴⁵ For example, only 1 staff member (5%), with a score of 281, was considering leaving their current position compared to 12–20% of providers in a study by Whitehead of inpatient critical care nurses, and compared to 20% of healthcare professionals in the validation study of the instrument.^{46,47} However, and as we discuss below, such comparisons between studies in substantially different contexts should be carefully scrutinized. Individual survey items with the highest composite scores in our sample were as follows:

1. Experienced that care was compromised due to lack of resources (item 17)
2. Experienced lack of administrative action or support for a problem compromising care (item 18)
3. Am required to work with abusive patients/family members who are compromising quality of care (item 22)

These results are comparable to previous studies in Brazilian hospitals where the following items were found to have higher means of distress: lack of competence of the working team; disrespect of the patient's autonomy; insufficient working conditions; and therapeutic obstinacy.^{48,49}

To better understand the results of the moral distress survey instrument, we asked participants to speak about potentially distressing aspects of their work and their strategies for coping with those issues. Three major themes emerged from analysis of these narratives: (1) a generalized hopelessness about the structural vulnerabilities and poverty faced by all Association clients; (2) a sense of hopelessness about changing any of these morally distressing circumstances; and (3) an emphasis on their personal capacity for empathy as the greatest and, sometimes, only form of care they could provide to needy families. Each of these themes in turn is discussed below.

Care and Hopelessness in Everyday Structural Violence

The political, economic, and structural factors that affect patients and their families in this Brazilian state are also influential in the moral dilemmas faced by staff at the Association, where demand for services is chronically high and distinctive types of stress (and distress) become regular for care providers and staff alike. The lead physician at the Association confirms that all of these sectors are inadequate in care and extremely hard to access:

ACS: What are the greatest barriers for these children in their lives?

Dr. Ferreira⁵⁰: The health part, right? The medical—the physiotherapy part, the surgery part, all of the assistance, of physiotherapeutic and psychological, psychiatric. I think there is a deficiency in all [of these treatment] sectors [and] they end up interconnecting.

The lack of medical treatment for these children with severe and life-threatening conditions was a repeated concern, with a secondary set of needs being support resources (e.g., wheelchairs, nutritional supplements) essential to keeping these young patients out of crisis.

Although Association staff narratives name these obstacles as evoking pressure and distress, somewhat unexpectedly, the results of staff surveys showed relatively low perceptions of distress. More precisely, despite the extreme poverty in which Association staff are working, there were no survey items

reported with an average composite score of 8 or higher (on a scale of 0 to 16). For example, survey item #17 states that staff experience the issue of “compromised care due to lack of resources, capacity of equipment, and space.” The mean frequency for this event was only 1.37 (with a corresponding mean intensity of 2.58), yet narratives consistently report a tremendous lack of resources. For example, the head nutritionist of the Child Health Association (Aline) explained the organization’s ultimate dependency on the failing public health sector:

Aline: For example, the medication issue. You have a family in SUS [the national healthcare system] that needs treatment, and you don’t have the specific medicine for that family.... Most of the time, they live very far away... families don’t have anything to eat, many times. So this frustrates me.

In response to survey item #4 (“Been unable to provide optimal care due to pressures from administrators or insurers to reduce costs”), staff reported a relatively high intensity of distress (2.789). Yet, again, mean responses to item #4 indicate this event occurred with very low frequency (0.8421).

Antônia: Look, Rio de Janeiro is a place where the public service leaves a lot to be desired. In the health system in Brazil, even private care has its defects. But those who depend on the public service end up having a great deficiency in care. It is more of a structural problem.

Aline: Where is our tax money going? We just pay taxes all the time, and we only see that there is no money, there is nothing. Rio is going through a terrible crisis. You know? And afterwards, we discovered that the governor of our state, who is imprisoned now, was getting all the money to give jewelry to his wife.

João: It’s precarious. And everyone from SUS received R\$5 billion last year, and this year they received R\$4 billion and something—like, reduced more than 1 billion.... And especially in the Baixada Fluminense (an extremely poor region in Northern Rio), health is very, very, very bad there. ... You go to a health post and they just talk, and give you an injection to lessen the pain, and that’s it. They don’t do any exams. They don’t do anything at all.

Dr. Ferreira: [We would like to have] more money so that we could offer more. [But] we have to let them go with a lot of [continuing medical] criteria.... It’s very hard.

Thus, even the lead physician at the Association, Dr. Ferreira knows that families are being “let go” before they are ready. This is not only part of the program’s designed limit but a necessity due to severe funding limitations.

Juliana: I feel pressure because we want to resolve these barriers, and then we get plagued by not being able to, and trying in all ways possible. We also know that we have to have our limit.... I feel frustrated sometimes because I know that here... even here, we still cannot resolve these issues.

Aline: Our work is very heavy mentally. Because we deal with sadness and frustration every day.

The deficits in resources and money, along with a lack of assistance from the public health system leaves staff frustrated. Staff see the Child Health Association as the most effective institution for solving the issues of their clients’ families, but are also discouraged by the government’s lack of support:

Dr. Mariana: Unfortunately, I worked more than 30 years in public service. We don’t have any prospects for improvement.

Inadequacies in medical and diagnostic care are common enough in the Brazilian slums known as favelas; exacerbating these challenges for families and staff are conflicts in the family and social contexts:

Dr. Fernanda: There's something else that's so bad. [It's] when you see that the family is very unstructured, to the point where you think that perhaps it would be better if this child were taken from this mother. Either because of violence, or the disease itself. So today, for example, we had a child who was very sick, who lived in a very poor community, [who had] a very unstructured family. And on Friday, she passed away. So, I think this may be the toughest decision, right? When should the child be removed from the family? Because the shelters are very bad too.

Thus, the community served by the Child Health Association is characterized by major disparities in health, income, and living situations which, in turn, make it very difficult for staff to care for their clients in ways they believe necessary and moral. Staff must *regularly* deal with these moral conflicts because the organization's mission is aimed at the poor and marginalized favela residents. Yet, Association staff nevertheless struggle with their own insufficiency in ways captured not in the survey instrument but in their narratives.

In the next section, we illustrate how staff's narratives contrast with their scores on the moral distress scale.

Characterizing Distress in Chronic Extreme Poverty

Given these broad patterns of structural violence and insufficient care for vulnerable patients across Rio de Janeiro, staff narratives of moral distress are somewhat distinctive. In comparison with staff experience of moral distress in higher-resource communities,^{51,52} these narratives should be viewed as what Scheper-Hughes called "reasonable responses to unreasonable constraints and contingencies."⁵³

At the Child Health Association, the programmatic design is intended to promote self-sufficiency and foster independence *within* those limited resources, and not to directly fill needs or repair gaps in services. In particular, there are limits on the number of people who can be seen, limited referring hospitals, and limits in the scope and duration of services at the Association. These limits must be explained to Association clients as they arrive, and regularly afterward. Explaining and enforcing these limits is a function staff find difficult and frustrating:

Antônia: My difficulty [is] in having to deny things.... We don't have things for everyone. We can't make exceptions, we can't. And then, like, you're in that situation of not being able to give [services]. And then you're like, "Fuck, I'm here providing a service that is meant to help the person, but I can't give it."

Sofia: It's the impotency of you not being able to do more, receive more families... and this ends up causing a conflict... "I'm doing what I can, but at the same time, I wanted to do more.... We even get sick because we see people in need, and we see that sometimes we are the only ones [who could help them]. It would be the only possibility of the family, the light at the end of the tunnel—and we can't do it because we have to limit [services]."

Thus, although staff reported (on the survey) only *infrequent* experiences with distressing events, they narrate regular, even daily limits and frustrations. These results may indicate staff are accustomed to a chronic lack of resources and do not experience personal distress over these circumstances, although they readily acknowledge the moral problem in open conversation with an interlocutor.

For the highly vulnerable patients of the Association, including children with life-threatening conditions, the chronic and structural neglect in which they live can be deadly. When a child dies from lack of access to care, a social worker who has been working at the organization for a few years, described it as a "heavy" day:

Juliana: When you see that case you are following is not going to work, you will ... lose a child, that unfortunately happens.... So, it's these things, punctual things that happen that I think, in my view, make the day heavier.... We don't have much [we can] do.

Juliana's narrative of not having "much [we can] do" in the case of a child's death points to the helplessness felt by Association staff about the public health sector. Survey item #8 may best capture this helplessness, as it states that staff "[participate] in care that causes unnecessary suffering or does not adequately relieve pain or symptoms." This item was not a frequent source of distress in our sample, as shown by a mean of 0.263, but when it occurred, it produced a high intensity of distress (mean of 3.263).

Some staff felt that the 2-year service cap, with short and few meetings within that time period, was simply not enough:

Lorena: My biggest difficulty is meeting my [own] expectations. I often see people who come with their self-esteem destroyed. [They] take courses, empower themselves, and suddenly get pregnant for different reasons, some of their own choosing, some unexpected. I feel helpless, frustrated, by a judgment that, at that moment, a dream was interrupted.

Juliana: Besides the pressure, I think the feeling becomes frustration, right. Because then we see that no matter how hard we are working, we can't reach it.

To cope with such regular and inherent feelings of helplessness and frustration, some staff members are determined to simply give what one could:

Antônia: Of course, I'm going to give support here, if it's once a month, I'll do my best to make this support the best. But like, it's a very difficult reality for you to handle in professional terms. How are you going to attend to this person in such a short time?

And in some instances, staff frustration leads to hopelessness directed at the public health sector:

Sofia: The impotence of us not—we want to do more—knowing you need to do more, but, at the same time, we don't [do enough]. If more people helped, if more people got sensitized—if the government was supporting us—because we're here doing nothing more than the role the government should do—the state should do it and it doesn't. So, we are. We keep fighting, but at the same time, we have our limits, right?

Debora: I direct clients to the public service... I know the service won't answer them the way it should.... Yeah, I feel frustrated. Yes. I don't have a solution, I see no solution—because it's not up to me.

In sum, Child Health Association staff experiences mirror that of other favela residents described by Scheper-Hughes, "who are forced to participate in the community's "space of death" by making innumerable, little "selections" that have life-and-death consequences."⁵⁴

As a reflection of having to make such "selections" on a regular basis, Association staff scores on the moral distress survey make sense. Moral dilemmas are frequent, and therefore staff cope by managing and approaching their distress in different ways. They become accustomed to everyday violence and, although they continue to witness and struggle with it, they do not report the levels of distress that might be seen in higher-resourced areas.

Coping Under Extreme Poverty

What, then, are those coping mechanisms that allow Association staff to deal with this materially inadequate and morally harmful context? The way they cope with these barriers and the tools they use to manage moral distress may provide novel insights for inter-cultural dialogue on the subject.

One strategy that played a central role was empathy. Empathy was repeatedly expressed as both a positive and necessary form of care for clients when material resources were thin for those families. Hanna argued that empathy is necessary for good care and can also contribute to moral conflicts in hospital settings.⁵⁵ At the Child Health Association, this is true. Staff noted that empathy for their clients is something that causes moral distress:

Aline: So, for example, [to] deny something [that clients have asked for] is very hard. [A mother may say,] “you are taking milk away from my son!” No. I am not taking it away. I want them to eat food, right? [Staff cannot give food after their two-year service has ended.] So, it’s very complicated.

Dr. Fernanda: There is no way you can offer everything to everyone. So, this is a collective health principle, right? You have to really prioritize those who are most serious or who will receive the most benefit... I wouldn’t say it’s exactly a conflict. It is much more a sadness than a conflict.

Antônia: What wears us out here are the moving stories... You get to know the person. So, if something happens to that person, you feel it too. It ends up creating a bond here.

So, although empathy creates sadness, it is also the main tool that Association staff use to empower families. One-on-one interactions are critical to truly understanding family needs, struggles, and stability:

Aline: We show love, we show care. Because outside they don’t get it... I think if you go see the families, they feel very good here. They thank us a lot. Because they are well taken care of, understand? They are seen.

Antônia: The affection, the empathy that employees have here to deal with these families and these children is an essential part of Saúde Criança which values holistic care and is very interdisciplinary. And of course, health matters, physical health, mental health, housing, profession, nutrition. But there is also this care, this affection they receive here. This is also a part of what helps in this structure [our program]. [Care creates] this support network [for staff].

Empathy allows staff members to hold back judgment and instead have an understanding for their clients’ circumstances:

Bárbara: My relationship [is] like this: I consider, I try as much as possible to deal with [clients] in such a language [that is] as simple as possible and [to] sometimes, put myself in their place, to put myself in place of the other even to understand. Because sometimes, we come with an attitude or with a posture of demanding without putting ourselves in the other’s place.... My role is understanding their difficulties, their roles, their lives and having a dialogue, in order to hear what they have to say, give space, give voice.

Aline: I think we see them as humans who deserve to be cared for like us. It is not because they are here [that] we have to treat [them]. They are people who are more needy. They are more humble. [They are] under the poverty line, but that doesn’t mean they should [lack] care, and there is a lot of social exclusion.... I think that they are automatically kind of excluded from society.

Underscoring the common conviction that empathy was a critical resource for their work, a second source of distress our participants expressed was colleagues who did not show empathy toward patients.

Dr. Ferreira: We have already observed the conduct of a doctor with a child in the hospital that we had to interfere in. The doctor called Child Protection Services for intervention...to say the child

wasn't clean. The mother was going through many difficulties: she had just had another child, [was] poor, she had no one to help her. This was a total lack of sensitivity by the doctor, and she called the High Council.

Amanda: We had a situation where we were trying very hard to strengthen this woman, to break this cycle of domestic violence. Other people, other professionals, spoke in a way that seemed to be legitimizing this violence. Like "Oh, she's that kind of a mom. I think they get dirty." I think that this is harmful... And we see that some other professionals, who don't have this social background, will often look at some situations with more judgment.

When a staff member is "required to work with other team members who are not as competent as family care requires," (survey item 13) staff on average reported this as somewhat distressful, with a frequency of 1 and a mean distress of 2.368 (composite score of 2.737). Narratives like the ones above therefore suggest that empathy is important to *both* the well-being of the families they care for and to their own well-being. Empathy extends to fellow staff, making them better able to handle the struggles of their clients.

Aline: The doctors really worry a lot. Everyone here works through love and because they like to work here. So, you see... people work here because they like to and want to help.

Livia: Rare are the employees here who don't understand you.

These various narratives reflect how staff view their program as effective, despite chronic struggles and limitations in services. In sum, providing empathy for patients—viewed as a key clinical function—inspires the need for empathy, competency, and support across various professionals. Moral distress in settings of such great hardship must, therefore, foment greater staff support networks than may be necessary for resource-rich clinics.⁵⁶

Discussion

This study of moral distress points to the need for ethical dialogue that explores deep differences in value systems.⁵⁷ Of the many factors reasonably likely to create moral distress for clinicians—like insufficient resources and futile care^{58,59,60}—all of these are severe and chronic in our research setting. Yet, only 1 of the 19 of the staff expressed a desire to leave the agency.⁶¹ What guidance can intercultural ethics provide when structural circumstances inform such deep inequity? Are institutions and structures of healthcare the only target of change,⁶² or do clinicians also have options and capacities for resiliency in these dilemmas?

Our ethnographic findings illustrate how moral distress is defined not solely by personal experiences with exceptional suffering, powerlessness within clinic dynamics, and a sense of futility. The chronicity of broader political-economic circumstances is also at play in clinician perceptions of distress. No individual item on the survey of moral distress received an average composite score of 8 or higher (survey scale 0–16). These findings support Ramos et al.'s⁶³ claim that moral distress is heavily influenced by the cultural and social environment. The population treated by the Association is among the poorest in Rio de Janeiro, for whom the public health system struggles to provide basic supports. Association staff narratives confirm that suffering is the norm.

Relatively few studies have assessed moral distress among care providers in resource-limited contexts where suffering is so familiar. In Uganda, conversations about moral distress included "frustration and hopelessness at participants' perceived inability to initiate change in the system."⁶⁴ Similarly, when creating an instrument to measure moral distress in Brazil, Ramos et al. identified a need to consider "the Brazilian political and social scene in which nursing coexists with diverse obstacles in practice."⁶⁵ In our own sample, moral distress scores were relatively low compared to other studies (Mean composite score:

60.8; Mean intensity: 71.8; Mean frequency: 20.1). These may be attributable, in part, to an overall familiarity with, and acceptance of the flaws in the Brazilian healthcare safety net. Providers insisted that, because of severe poverty and the lack of an effective social safety net, things will always be like this, expressing “helplessness” and the need to “make the best” of a desperate situation.

Yet, we also identified unique forms of coping with these everyday stressors. Association staff pointed to the holistic structure of their program and frequent communication across staff in weekly staff meetings. These meetings foster cooperation and communication on the most complex of cases,⁶⁶ and offering biweekly therapy sessions for staff to allow them opportunities to discuss their own pressures and struggles. Such strategies are a model that may be useful in other settings of chronic moral distress and gaps in care.⁶⁷⁻⁶⁸

Finally, a paradox identified in our research is that of empathy among clinicians. Staff narratives relate their pride in giving empathy to their clients, for the growth it promotes and because it can alleviate clinicians’ own moral distress. Yet, empathy has been described in several studies as a major *cause* of moral distress.^{69,70,71} By definition, empathy is a capacity to fully understand the situations of their clients and to share feelings about those circumstances. Therefore, it may be that providing care for disadvantaged populations when combined with empathy can actually simultaneously produce and combat moral distress. Our results are the first of which we are aware to shed light on this paradoxical process.

Limitations of the study include lack of generalizability due to the use of a non-governmental organization with a very small sample size. Although this study addressed almost all direct care staff at the organization, there were not sufficiently large numbers to make broad generalizations to other settings, types of organizations, or staff. Also and as cautioned by Ann Hamric (personal communication), the moral distress survey instrument is a relatively new instrument created and validated in American hospital settings; ours was not a validation study of this tool but an ethnographic study utilizing survey results for data triangulation and exploratory purposes. Study replication with a larger sample in the Brazilian context of public health assistance is warranted.

Conclusion

Although moral distress among American health professionals has received greater attention in recent decades, the moral reactions and coping strategies of healthcare personnel in conditions of chronic extreme poverty have not been given adequate attention. Moral distress is likely to emerge in contexts of poverty and structural violence due to insufficient resources, over-work, and impotence of staff to change these conditions for their patients.

Our research reveals the unique coping strategies of staff working among a favela population and suggests that a deeper understanding of the complexities of their moral distress can be captured by a mixed-methods research approach. Similarly, these contexts require different structures and strategies for care, such as nongovernmental organizations and greater social support services. Staff especially need skills and resources to promote resilience and coping, since treatments and medicines are in short supply. Finally, our work contributes to nascent discussions of moral distress in resource-limited contexts around the world, and to efforts to better understand and measure the effects of local context on perceptions of moral distress. Intercultural ethical approaches to conditions of chronic moral distress will not only shed better light on these complex settings but also capture the strengths and resiliencies of the people living in them.

Acknowledgments. We gratefully acknowledge funding from the following programs at Southern Methodist University: Cary M. Maguire Center for Ethics and Public Responsibility, Richter International Fellowship Program, Hamilton Undergraduate Research Scholars Program, and Engaged Learning Fellowship Program.

Conflicts of interest. The authors declare none.

Notes

1. Hardin G. Stimulus/response: Lifeboat ethics: The case against helping the poor. *Psychology Today* 1974;**8**(4):38.
2. Scheper-Hughes N. *Death Without Weeping*. Berkley: University of California Press; 1992.
3. See note 2, Scheper-Hughes 1992.
4. Massé R. Between structural violence and idioms of distress: The case of social suffering in the French Caribbean. *Anthropology in Action* 2007;**14**(3):6–17.
5. Smith-Morris C. Care as virtue, care as critical frame: A discussion of four recent ethnographies. *Medical Anthropology* 2018;**37**(5):426–32.
6. See note 2, Scheper-Hughes 1992.
7. Scheper-Hughes N, Bourgois P. *Violence in War and Peace: An Anthology*. Malden, MA: Blackwell; 2004.
8. Dalmolin GdL, Lunardi VL, Lunardi GL, Barlem ELD, Silveira RSD. Nurses, Nursing technicians and assistants: Who experiences more moral distress? *Revista da Escola de Enfermagem da USP* 2014;**48**(3):521–9.
9. Harrowing JN, Mill J. Moral distress among Ugandan nurses providing HIV care: A critical ethnography. *International Journal of Nursing Studies* 2010;**47**(6):723–31.
10. Ramos A, Barlem E, Barlem J, Rocha L, Dalmolin G, Figueira A. Cross-cultural adaptation and validation of the moral distress scale-revised for nurses. *Revista Brasileira de Enfermagem* 2017;**70**(5):1011–7.
11. Ulrich CM. Ebola is causing moral distress among African healthcare workers. *British Medical Journal* 2014;**349**(1):g6672.
12. Schroeder D. Human rights and their role in global bioethics. *Cambridge Quarterly of Healthcare Ethics* 2005;**14**:221–3.
13. Sargent C, Smith-Morris C. Questioning our principles: Anthropological contributions to ethical dilemmas in clinical practice. *Cambridge Quarterly of Healthcare Ethics* 2006;**15**:123–34.
14. Jameton A. *Nursing Practice: The Ethical Issues*. Englewood Cliffs, N.J.: Prentice-Hall; 1984.
15. Hanna DR. Moral distress: The state of the science. *Research and theory for nursing practice*. 2004;**18**(1):73.
16. McCarthy J, Deady R. Moral distress reconsidered. *Nursing Ethics* 2008;**15**(2):254–62.
17. Koch T. *Ethics in Everyday Places: Mapping Moral Stress, Distress, and Injury*. 2018, Esri Press, Redlands CA.
18. See note 14, Jameton 1984.
19. Fourie C. Who is experiencing what kind of moral distress? Distinctions for moving from a narrow to a broad definition of moral distress. *AMA Journal of Ethics* 2017;**19**(6):578.
20. Campbell SM, Ulrich CM, Grady C. A broader understanding of moral distress. *American Journal of Bioethics* 2016;**16**(12):2–9.
21. Originally coined by Johan Galtung, the term ‘structural violence’ describes harm caused when social structures or institutions systematically prevent people from meeting their basic needs, premature death, or unnecessary disability. [Galtung J. 1969. Violence, peace, and peace research. *Journal of Peace Research* 1969;**6**(3):167–91.]
22. See note 9, Harrowing, Mill 2010, at 723–31.
23. Dalmolin explains “insufficient conditions” as “related to the work organization, associated with lack of material resources and also, to work overload caused by insufficient human resources” (2014:520).
24. See note 10, Ramos et al. 2017, at 1011–7.
25. See note 9, Harrowing, Mill 2010, at 723–31.
26. Smith-Morris C. *The Chronicity of Life, The Acuteness of Diagnosis. Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*. New Brunswick, NJ: Rutgers University Press; 2010:21–37.
27. See note 1, Hardin 1974 and also see note 2, Scheper-Hughes 1992.
28. Almeida C. *Do esplendor à crise, a história do Rio*. Globo; 2017; available at <https://oglobo.globo.com/rio/do-esplendor-crise-historia-do-rio-21863999> (last accessed 24 Mar 2021).

29. Flawed but fair: Brazil's health system reaches out to the poor. *Bulletin of the World Health Organization [Internet]* 2008;86:241–320.
30. See note 29, *Bulletin of the World Health Organization* 2008.
31. Serra CG, Rodrigues PHdA. Avaliação da Referência e Contrarreferência no Programa Saúde da Família na Região Metropolitana do Rio de Janeiro (RJ, Brasil). *Ciência & Saúde Coletiva* 2010;15:579–3586.
32. Congenital Anomalies: World Health Organization 2016; available at <https://www.who.int/news-room/fact-sheets/detail/congenital-anomalies> (last accessed 24 Mar 2021).
33. Pinto LF, Soranz D, Scardua MT, Silva IdM. A Regulação Municipal Ambulatorial de Serviços do Sistema Único de Saúde no Rio de Janeiro: Avanços, Limites e Desafios. *Ciência & Saúde Coletiva* 2017;22:1257–1267.
34. Whitehead PB, Herbertson RK, Hamric AB, Epstein EG, Fisher JM. Moral distress among healthcare professionals: Report of an institution-wide survey. *Journal of Nursing Scholarship* 2015;47(2):117–25.
35. Streiner DL, Saigal S, Burrows E, Stoskopf B, Rosenbaum P. Attitudes of parents and health care professionals toward active treatment of extremely premature infants. *Pediatrics* 2001;108(1):152–7.
36. Trotochaud K, Coleman JR, Krawiecki N, McCracken C. Moral distress in pediatric healthcare providers. *Journal of Pediatric Nursing* 2015;30(6):908–14.
37. Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics* 2006;117(1):e48.
38. Harrison H. The offer they can't refuse: Parents and perinatal treatment decisions. *Seminars in Fetal and Neonatal Medicine* 2008;13(5):329–34.
39. Our Results: Saúde Criança; available at <https://www.saudecrianca.org.br/> (last accessed 6 May 2020).
40. About Us: Saúde Criança; available at <https://www.saudecrianca.org.br/en/quem-somos/>. Perguntas Frequentes: Ministerio da Cidadania; available at <http://mds.gov.br/aceso-a-informacao/perguntas-frequentes/bolsa-familia/beneficios/beneficiario> (last accessed 6 May 2020).
41. Perguntas Frequentes: Ministerio da Cidadania; available at <http://mds.gov.br/aceso-a-informacao/perguntas-frequentes/bolsa-familia/beneficios/beneficiario> (last accessed 24 Mar 2021).
42. See note 39.
43. Smith-Morris C. When numbers and stories collide: Randomized controlled trials and the search for ethnographic fidelity in the veterans administration. In: Adams V, ed. *Metrics: What counts in global health*. Durham, NC: Duke University Press; 2016.
44. Epstein EG, Whitehead PB, Prompahakul C, Thacker LR, Hamric AB. Enhancing understanding of moral distress: The measure of moral distress for health care professionals. *AJOB Empirical Bioethics* 2019;10(2):113–24.
45. See note 44, Epstein et al. 2019, at 113–24.
46. See note 34, Whitehead et al. 2015, at 117–25.
47. See note 44, Epstein et al. 2019, at 113–24.
48. See note 8, Dalmolin et al. 2014, at 521–9.
49. Fernandez-Parsons R, Rodriguez L, Goyal D. Moral distress in emergency nurses. *Journal of Emergency Nursing* 2013;39(6):547–52.
50. All names are pseudonyms.
51. Elpern E, Covert B, Kleinpell R. Moral distress of staff nurses in a medical intensive care unit. *American Journal of Critical Care* 2005;14(6):523–30.
52. Kälveborn S, Höglund AT, Hansson MG, Westerholm P, Arnetz B. Living with conflicts-ethical dilemmas and moral distress in the health care system. *Social Science & Medicine* 2004;58(6):1075–84.
53. See note 2, Scheper-Hughes 1992, at 400.
54. See note 2, Scheper-Hughes 1992, at 407.
55. See note 14, Hanna 2004, at 73.

56. On the negative impacts of competition among providers in resource scarce environments, see Siddiqui S, Smith-Morris C. Professional competition amidst intractable maternal mortality: Midwifery in rural Pakistan during the COVID-19 pandemic. *Social Science & Medicine* 2022; **313**:115426.
57. See note 12, Schroeder 2005, at 221.
58. See note 9, Harrowing, Mill 2010, at 723–31.
59. See note 24, Whitehead et al. 2015, at 117–25.
60. Hamric AB, Borchers CT, Epstein EG. Development and testing of an instrument to measure moral distress in healthcare professionals. *AJOB Primary Research* 2012;3(2):1–9.
61. See note 44, Epstein et al. 2019, at 113–24.
62. Emanuel LL. Ethics and the structures of healthcare. *Cambridge Quarterly of Healthcare Ethics* 2000;9:151.
63. See note 10, Ramos et al. 2017, at 1011–7.
64. See note 9, Harrowing, Mill 2010, at 723–31.
65. See note 10, Ramos et al. 2017, at 1011–7.
66. See note 52, Källemark et al. 2004, at 1075–84.
67. Beck J, O'Hara KL, Falco CN, Bassett HK, Randall CL, Cruz S, et al. How attendings can help residents navigate moral distress: A qualitative study. *Academic Pediatrics* 2021;21(8):1458–66.
68. Nichter M. From idioms of distress, concern, and care to moral distress leading to moral injury in the time of Covid. *Transcultural Psychiatry* 2022;59(4):551–67.
69. See note 9, Harrowing, Mill 2010, at 723–31.
70. See note 15, Hanna 2004, at 73.
71. Brazil K, Kassalainen S, Ploeg J, Marshall D. Moral distress experienced by health care professionals who provide home-based palliative care. *Social Science & Medicine* 2010;71(9):1687–91.