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Moral Distress and Resilience Associated with Cancer Care Priority Setting in a Resource-Limited Context

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Abstract

Background. Moral distress and burnout are highly prevalent among oncology clinicians. Research is needed to better understand how resource constraints and systemic inequalities contribute to moral distress in order to develop effective mitigation strategies. Oncology providers in low- and middle-income countries are well positioned to provide insight into the moral experience of cancer care priority setting and expertise to guide solutions.

Methods. Semistructured interviews were conducted with a purposive sample of 22 oncology physicians, nurses, program leaders, and clinical advisors at a cancer center in Rwanda. Interviews were recorded, transcribed verbatim, and analyzed using the framework method.

Results. Participants identified sources of moral distress at three levels of engagement with resource prioritization: witnessing program-level resource constraints drive cancer disparities, implementing priority setting decisions into care of

individual patients, and communicating with patients directly about resource prioritization implications. They recommended individual and organizational-level interventions to foster resilience, such as communication skills training and mental health support for clinicians, interdisciplinary team building, fair procedures for priority setting, and collective advocacy for resource expansion and equity.

Conclusion. This study adds to the current literature an in-depth examination of the impact of resource constraints and inequities on clinicians in a low-resource setting. Effective interventions are urgently needed to address moral distress, reduce clinician burnout, and promote well-being among a critical but strained oncology workforce. Collective advocacy is concomitantly needed to address the structural forces that constrain resources unevenly and perpetuate disparities in cancer care and outcomes. *The Oncologist* 2021;26:e1189–e1196

Implications for Practice: For many oncology clinicians worldwide, resource limitations constrain routine clinical practice and necessitate decisions about prioritizing cancer care. To the authors' knowledge, this study is the first in-depth analysis of how resource constraints and priority setting lead to moral distress among oncology clinicians in a low-resource setting. Effective individual and organizational interventions and collective advocacy for equity in cancer care are urgently needed to address moral distress and reduce clinician burnout among a strained global oncology workforce. Lessons from low-resource settings can be gleaned as high-income countries face growing needs to prioritize oncology resources.

Introduction

Burnout is highly prevalent among oncologists [1]. A recent Special Series in *JCO Oncology Practice* devoted to this topic declared an urgent imperative to understand drivers of clinician burnout and test solutions [2]. Moral distress is considered a root cause of clinician burnout [3]. In a Call to Action from the American Society of Clinical Oncology

Ethics Committee, many important factors associated with oncologist burnout were recognized, including moral distress related to ethical challenges in end-of-life care [4]. However, the effects of resource constraints and systemic inequalities have been absent from this discourse.

Moral distress arises when one is unable to act in accord with their ethical values because of external constraints, resulting in negative emotions [5]. For many oncology clinicians worldwide, resource limitations constrain routine clinical practice and necessitate decisions about prioritizing cancer care. Priority setting, an umbrella term that encompasses both resource allocation and rationing, occurs at all levels of the health care system, from governments to hospitals to "bedside" patient care [6]. When explicit priority setting systems are not in place, resources tend to be distributed arbitrarily or based on ability to pay. Cancer care priority setting decisions, whether explicit or implicit, can significantly impact individual patient outcomes and perpetuate disparities. Research from other health care disciplines indicates that the need to prioritize limited resources causes moral distress among clinicians in both high- and low-resource settings [7–10]. In oncology, qualitative studies from high-income countries (HICs) with national health care systems suggest that cancer care priority setting decisions negatively affect discussions and relationships between oncologists and patients [11, 12]. Further research is needed to understand the impact of resource limitations and prioritization on oncology clinicians.

Oncology providers in low- and middle-income countries (LMICs), where resource constraints are pronounced, are uniquely positioned to provide insight into the moral experience of cancer care priority setting and expertise to guide solutions. LMICs face an unprecedented growth in cancer burden and disproportionate share of global cancer deaths [13]. Although major progress has been achieved in the fight against cancer, many services are still not widely available in LMICs [14]. Vast disparities in access to preventive measures, screening, early detection, and effective treatment translate into millions of avoidable and premature deaths [15]. In Africa, the cancer burden is steadily rising, and health care systems are inadequately equipped to meet population needs [16]. For example, radiotherapy is essential to effectively treat the most common cancers in LMICs, yet there is a severe worldwide shortage of radiotherapy capacity, and approximately half of African countries have no radiation machine [17, 18]. In addition, many highly effective cancer drugs are not available to much of the world's population [19].

Because of these constraints, oncology programs and providers in LMICs face priority setting decisions on a routine basis. The impact of these decisions on oncology clinicians has not been characterized, and there is a paucity of research on moral distress in low-resource settings generally [20]. Yet, moral distress represents an important potential target for intervention to prevent clinician burnout and promote well-being of a strained global oncology workforce [21, 22]. Furthermore, lessons learned from LMICs can be leveraged as HICs face growing needs to prioritize oncology resources because of soaring prices of novel cancer therapeutics, drug shortages, and improved survival requiring long-term treatment. Moreover, the COVID-19 pandemic has imposed new constraints on health care systems throughout the world, and oncologists in many settings will be impacted by excess cancer-related deaths related to economic crisis [23, 24]. Understanding how structural inequalities drive clinician moral distress is also highly relevant for oncologists caring for patients without insurance in the U.S. This article describes the moral experience and recommendations of oncology clinicians, advisors, and program leaders engaged in clinical priority setting at a cancer center in Rwanda.

MATERIALS AND METHODS

Setting

Butaro Hospital is a district hospital in rural Rwanda run by the Ministry of Health and supported by the nongovernmental organization Partners In Health, locally known as Inshuti Mu Buzima (PIH/IMB). In 2012, the first cancer treatment facility in Rwanda was established at Butaro Hospital through international partnership, with a mission to deliver high-quality cancer care for poor and rural populations [25]. Butaro Cancer Center of Excellence (BCCOE) provides basic services across the cancer care continuum, including pathologic diagnosis, surgery, chemotherapy, palliative care, and psychosocial support. Oncology care is delivered by local and international internists, pediatricians, general practitioners, and nurses in routine consultation with U.S.–based oncology specialists ("advisors").

Because of resource constraints, the scope of practice at BCCOE is deliberately limited to a subset of cancers that are curable or effectively palliated with affordable treatments that can be delivered safely in this setting. Until 2019, there was no radiotherapy facility in Rwanda, and PIH/IMB was able to support a finite number of patients per month to receive radiotherapy in neighboring countries. As the need for radiotherapy increasingly outstripped supply at BCCOE, patient selection processes evolved. Referral decisions were transferred from individuals to a group of clinicians during regular selection meetings, and prioritization guidelines designed to maximize lives saved were developed. Patients who were not able to receive radiotherapy were treated with other modalities if indicated or with palliative care.

Study Design and Participants

This article reports on a subset of themes from a qualitative interview study aimed at understanding the experience and views of oncology clinicians, advisors, and program leaders engaged in clinical priority setting and patient care at BCCOE. Purposive sampling was used to recruit oncology physicians (MDs) and nurses (RNs) (collectively "clinicians"), past and present program leaders (PLs), and U.S.–based oncology specialists who serve as clinical advisors. Participants were recruited onsite at BCCOE through verbal invitation or offsite by e-mail. The study was led by a former oncology physician now clinical advisor and researcher at BCCOE (R.J.D.) and the BCCOE Director of Oncology (C.S). Recruitment and interviews were conducted by R.J.D. To protect anonymity, here we refer to Rwandan and other

East African participants as "Local" and participants from outside East Africa as "International."

This study was approved by the Rwanda National Ethics Committee, the Inshuti Mu Buzima Research Committee, and the Institutional Review Board of the University of California, San Francisco.

Data Collection

Semistructured interviews were conducted between October 2018 and February 2019. An interview guide was developed by a multidisciplinary team of study investigators based on their knowledge of priority setting at BCCOE, patient care experience, and a review of relevant literature. After the first two interviews, the guide was revised to enhance clarity and flow. Participants provided written informed consent. Interviews were conducted in English, audio-recorded, and transcribed verbatim. Transcripts were deidentified to protect confidentiality.

Data Analysis

Textual data were analyzed using the framework method of thematic analysis [26]. Members of our multidisciplinary research team performed the analysis, contributing expertise in oncology, bioethics, and qualitative research. A working analytical framework was developed through a combination of a priori concepts from the interview guide and themes that emerged inductively during an initial open coding process. All transcripts were independently coded by R.J.D. and one of two coinvestigators (E.M. or C.N.). Intercoder agreement was assessed for each transcript, and discrepancies were reviewed by both coders and adjudicated through discussion. The framework was continually refined throughout the coding process. Matrices for each conceptual category in the framework were created in spreadsheets, with themes represented by columns and participants by rows. Textual data were charted into the matrices. Data were summarized and interpreted by column. Data management and analysis were facilitated by MAXQDA (VERBI Software, Berlin, Germany) and Microsoft Excel software.

RESULTS

Characteristics of the 22 participants are presented in Table 1. Engagement with resource prioritization occurred at three levels: (a) witnessing program-level resource constraints drive cancer disparities; (b) implementing priority setting decisions into care of individual patients; and (c) communicating with patients directly about resource limitations and prioritization. Participants described sources of moral distress and strength experienced at each level and recommended strategies to foster resilience and reduce burnout (Table 2).

Program-Level Priority Setting

Participants widely embraced the BCCOE mission to deliver high-quality cancer care for underserved populations yet described tension between this ambitious mission and the reality of resource constraints that inherently limit care.

Table 1. Participant and interview characteristics ($n = 22$)

Participant Characteristics	n (%)
Gender	
Female	7 (32)
Male	15 (68)
Role(s) at Butaro	
Oncology nurse	3 (14)[a]
Oncology physician	13 (59)[a]
Program leader	7 (32)[a]
Clinical advisor	4 (18)[a]
Role status at time of interview	
Former	5 (23)
Current	17 (77)
Nationality	
Rwandan	9 (41)
American	9 (41)
Other	4 (18)
Local vs. international classification	
Local	11 (50)
International	11 (50)
Interview characteristics	
In-person	14 (64)
Mean duration (range), min	52 (32–91)
Telephone	8 (36)
Mean duration (range), min	46 (25–62)

[a]Categories are overlapping; percentages do not add up to 100%.

"It was not easy because Rwanda with Partners In Health thought that all cancer patients deserve to be treated. But there's no way to treat all of them." (P18; Local MD/PL)

In order to maximize the available resources for cancer care at BCCOE, deliberate decisions were made about which cancers to treat, at which stages, and with what therapies. Participants conveyed the challenge of being able to treat some patients but not others because of resource constraints.

"We have been very careful at dissecting out where we thought we could have the biggest impact and focusing our efforts and resources in those lines. And that's very hard for the clinicians on the ground because they are seeing patients with diseases that are not on that list, where there may be some palliative benefit of therapy, but it's not great—and frankly we have to make choices between treating a locally advanced breast cancer patient for cure versus a lung cancer patient to prolong their life for a month or two. Both our Rwandan-based doctors and our U.S. advisors struggle with that." (P12; International PL)

Participants also emphasized the emotional difficulty of recognizing that BCCOE treatment protocols, adapted to fit local health care infrastructure, were suboptimal compared with standards of care in HICs. They highlighted specific

Table 2. Sources of moral distress and resilience at three levels of engagement with cancer care priority setting

Dimension	Specific drivers of moral distress	Recommendations for resilience
Program-level oncology capacity	Tension between program values and reality imposed by resource constraints Determining what falls within versus outside scope of practice Disparities between international and local standards of cancer care Unjust structural inequalities at the root of resource constraints	Institutional culture of pragmatic solidarity in delivering high-quality care to poor patients Development of innovative models of cancer care for diverse contexts Collective advocacy for expanded cancer care resources and equity Clinician engagement in program-level priority setting
Patient-level oncology care	Inability to treat patients who could be treated in a high-resource setting Obligation and power to prioritize one individual over another, i.e., "play God" Inadequate clinical information and locally relevant data to guide decision-making Role conflict between resource stewardship and moral obligation to patient Conflicting values among colleagues Inability to provide financial support to patients based on nationality	Objective evidence-based criteria for prioritization Locally relevant real world clinical data collection Assessment of relevant ethical values for incorporation into priority setting Priority setting decisions by multidisciplinary group rather than individual clinicians Strengthened clinical systems, i.e. for cancer staging Social and financial support to eliminate socioeconomic barriers to care
Patient-clinician communication	Informing patients that no treatment options are available when they exist in high-resource settings Deciding whether to disclose the need for treatment that is likely inaccessible Explaining complex priority setting decisions to patients with low education and health literacy	Communication skills training Team debriefs about priority setting decisions Mental health counseling services Social activities for interdisciplinary team building

examples of resources that are routinely needed but unaffordable, such as targeted therapies.

"We calculated how many lives we lose every year because we don't have trastuzumab. Those are people who are dead who could be alive. But if you look at the cost of trastuzumab versus the main income in the country or spending per capita on health care, it's off the charts." (P12; International PL)

Tension between program ideals and the reality imposed by resource constraints was most pronounced in discussions about prioritizing patients for scarce radiotherapy resources.

"The oncology program is for treating poor people, and to respect equity among patients. If you have 100 patients who need radiotherapy, for example, and we send ten, it's not equity. We do the selection, we have criteria—but all patients who have indication for radiotherapy don't have the same chance." (P05; Local MD)

Despite the inability to provide the highest standards of cancer care for all patients, taking part in a deliberate pragmatic effort to reduce disparities activated clinicians' sense of commitment, control, and self-efficacy.

"Care that these people would never access—care that is only available in the capital city or in other countries— we have brought to the poor." (P07; Local MD)

"It's always terrible when people's outcomes or access to treatment is poor, but that's why you're doing the work, to try and remove those barriers and improve their access to care. So, it is hard, but you understand that it is in service of correcting those disparities." (P15; International MD)

Patient-Level Priority Setting

As difficult as facing program-level constraints was for participants, the act of implementing them in the care of individual patients generated the most distress.

"If you find a patient's not in the scope [of practice at BCCOE], and you see in other countries he can be cured, but you tell him go back home, it really affects us very much." (P19; Local PL)

Many conveyed distress associated with bearing the responsibility for selecting patients for potentially life-saving radiotherapy when only a fraction of those who needed it could be sent.

"It's very stressful. You sort of play God when you're choosing who gets to get treatment. (P07; Local MD) What is really hard is to prioritize one over the other. Actually it is really very, very, very, hard for me to… I make a joke that we shall have indemnity for doing that job." (P21; Local MD)

"You think over time it would get easier, but it only gets harder. And it gets emotional… Everybody has their own

personal priorities—I hate to say the word "deserve," but who deserves radiation. Where in other countries everybody gets it, or almost everyone. It's a weird thing to be picking who gets something that could be so life changing. So you see that in people, how it affects them." (P20; International MD)

Compounding the difficult obligation to prioritize patients, the clinical information that determined these decisions was often incomplete.

"Some of the staging was not super reliable, but we had to use that to base really significant decisions for individual people. That was certainly part of the emotional strain, and I would expect contributes to clinician burnout." (P17; International MD)

Despite the distress related to rationing care at the patient level, several participants embraced their dual role as stewards of scarce resources. Understanding and accepting the need for patient-level priority setting in order to maximize benefits on a program or societal level was part of an active coping style.

"I have to think as a clinician who wants to improve the survival for my patient, but also as economist who has to use effectively the resources we have." (P01; Local MD)

They also emphasized the gratification and fulfillment of providing care for high-priority patients who may not otherwise be able to access it.

"We have some survivors who are still living until now. It's like a solace—for those who get the chance to get radiation, they are cured, and we have some solace from that; that's really a good thing that we did, that's rewarding." (P19; Local PL)

Communication with Patients and Families

Explaining to patients that no treatment options were available because of resource constraints was especially challenging.

"Now patients can read, they are informed… even the doctors tell them, you can prolong your life on radiotherapy, but we are prioritizing those patients that we can cure… You get really affected when you announce such news; 'nothing else we can do, but you can prolong if you have this and this.'" It's so bad. (P02; Local MD)

Participants had conflicting views regarding the decision to tell a patient that they would benefit from a treatment that might not be available to them, such as stem cell transplant or radiotherapy. Some believed that informing them does more harm than good, whereas others advocated for disclosure in case patients might be able to find funds.

"It is frustrating on both sides. The doctor or nurse who's explaining, and the patient who is hearing "I could be cured but because of issue of money, I will die." That's the message… It's better that you don't even tell her that there is a cure." (P04; Local RN)

"I tell patients two things: most especially, this cancer is cured by radiotherapy, and we cannot provide radiotherapy to you given the number of patients that we have. Can you ask your family to step in and support you?" (P02; Local MD)

Recommended Strategies

At the individual level, participants proposed communication skills training and internally standardized messaging for discussing resource prioritization with patients. They also advocated for mental health support for clinicians, professional development opportunities to promote job-related fulfillment, and involving leadership in burnout prevention.

"[Communication training] would give clinicians the words and the language to use in those very tough, uncomfortable situations. (P14; International PL)

One thing that we need to have is clinician support. How do we support our clinicians—to vent? And to cope—psychosocial support, if you will. For oncology it's critical. 'Cause the pressure is really high. (P09; Local PL)

If we could get time, just to help in the burnout process, to leave the work, get a vacation, or awards to go to a conference somewhere. And also involve leadership to help in the management of burnout or stress that may be left because of those hard decisions. (P19; Local PL)"

At the organizational level, participants emphasized procedural improvements to priority setting such as refining objective criteria to guide prioritization decisions, transferring the burden of decision-making from individual clinicians to a group, and facilitating consultation with advisors.

"It's already a really hard choice to send one patient and not another for truly life-saving treatment… More objective criteria allow you to de-personalize the decision, so that you feel like you are making an informed, medically-sound, evidence-based decision." (P15; International MD)

They also recommended team debrief sessions about priority setting decisions.

"Clinicians, nurses, doctors—a debriefing, maybe on a quarterly basis, on how they feel about their decisions, or even in hindsight, if they think they could have done it better, that loop is not there. We have not really had a chance to sit and reflect. How do you think, collectively, we can improve?" (P09; Local PL)

Across the board, participants' strongest recommendation was to expand the resources available to treat and prevent cancer in Rwanda, calling for raising public awareness and advocacy for cancer care.

"We need more resources, so people don't have to make these difficult prioritization decisions. (P09; Local PL)

If you had community awareness, then people—even Rwandans, not just charity—might feel like we shall participate to cover all possible [cancer] cases we can cover. We can find ways… For me it's not a matter of lacking funds. It's prioritization, and ways to get the funds. The funds are somewhere. I think if people were aware they would be more mobilized for this." (P21; Local MD)

DISCUSSION

Explicit and implicit cancer care priority setting influences routine patient care for many oncology clinicians globally. The contributions of resource constraints and inequities to moral distress and clinician burnout across various settings are not well understood. Our study addresses the need to examine the impact of cancer care priority setting on oncology clinicians in a low-resource setting. From a context in which resource constraints are amplified and deliberate efforts are made to set priorities within a social justice framework, unique insights can be gleaned that are potentially transferrable to a wide variety of settings. We identified three dimensions of engagement with resource priority setting that generate moral distress and present distinct opportunities for resilience strategies. Resilience, the capacity to cope with, overcome, and become strengthened by adversity, is a key protective factor against burnout [27]. Resilience is a skill that can be learned and fostered through individual- and organizational-level interventions [27–29]. Collective advocacy is concomitantly needed to address the structural forces that constrain resources unevenly and perpetuate disparities in cancer care and outcomes [3, 10, 30].

First, resource availability for cancer care in Rwanda exposes stark disparities between local and international standards, reflecting pervasive global inequities. The inability to provide the highest standard of care to all patients creates the conditions for moral distress. At the same time, taking part in the day-to-day work of providing high-quality cancer care for poor and rural populations and reducing unjust disparities activated clinicians' sense of commitment, control, and self-efficacy. Thus, the institutional culture of BCCOE, which emphasizes the mission to make health care a human right and provide a preferential option for the poor in cancer care, fostered resilience [31]. Yet, while participants derived fulfillment and optimism from the dramatic progress that has been made in oncology capacity building in Rwanda, they strongly advocated to urgently expand resources for cancer control and further elevate the standards of care.

Second, implementing priority setting decisions in the care of individual patients caused significant moral distress. In practice, these decisions translated into a subset of cancers that could routinely be treated at BCCOE, a subset that

definitively could not, and a "gray area" in between. Clinicians felt frustration and grief when seeing patients who could not be treated in Rwanda but might have been cured in a high-resource setting with specialized therapies such as stem cell transplant, for example. Navigating grayer areas, such as rare or advanced cancers that may be treated on a case-by-case basis at BCCOE or interventions near the margins of affordability for a patient or the program, was also challenging. Prioritizing patients for scarce radiotherapy resources was a major specific source of distress; clinicians felt very uncomfortable wielding the power to decide whether a patient received curative radiotherapy.

In addition to the urgent need for resource expansion, these challenges underscore the importance of fair procedures for priority setting in mitigating moral distress. Establishing objective criteria to define the scope of clinical practice and guide patient prioritization for scarce resources reduces the emotional burden of navigating gray areas. Transferring decision-making from individual clinicians within patient interactions to a group of clinicians and advisors within a structured decision-making procedure promotes consistency and alleviates distress. Although implementing priority setting decisions was difficult, several participants acknowledged that explicit priority setting maximizes the benefits of limited resources, avoids arbitrary or inequitable allocation, and is required for sustainability of the program. Understanding and accepting the need for resource stewardship facilitated active coping with patient-level prioritization. Thus, increased clinician awareness and engagement with program-level priority setting decisions fostered resilience.

Third, communicating with patients and families directly about resource constraints and prioritization within the context of a therapeutic relationship caused significant distress. Clinicians emphasized the difficulty of informing patients that they will not be treated when they know that treatment does exist in high-resource settings; of being the one to put this injustice into words. Views were mixed about the appropriateness of disclosing a patient's need for a treatment they are unable or unlikely to receive. Standardized messaging about priority setting decisions and formalized communication skills training could mitigate the burden of ad hoc discussions. Recently, serious illness communication programs in HICs have developed tools for communicating with patients about resource allocation in anticipation of scarcity because of the COVID-19 pandemic [32, 33], which could be adapted for diverse contexts. Participants also advocated for team debrief sessions about priority setting decisions, mental health counseling services for clinicians, and community-building activities to enhance peer support.

The literature on addressing burnout in oncology has focused on promoting resilience through individual- and organizational-level interventions such as burnout education, mindfulness training, and assessment of clinician well-being as a quality metric [4, 27]. Some suggestions from our participants, such as communication training and team building, are recommended in this literature as well. Our findings contribute additional individual- and organizational-level strategies that are specific to mitigating moral distress caused by priority setting, yet also demand a more proximal or "upstream" approach to addressing the structural forces

that constrain resources and perpetuate disparities. The connection between clinician burnout and the experience of caring for marginalized patients facing the ongoing harms of poverty and oppression receives insufficient attention but presents a key opportunity for action [30]. Whereas oncology clinicians may feel demoralized as they treat patients whose risk of dying from cancer is determined by structural inequalities, they may derive substantial empowerment from uniting together to promote equity. Collective advocacy is both a strategic and therapeutic antidote to burnout [3, 30].

Our study should be interpreted in light of its limitations. BCCOE, a collaboration between a government, nongovernmental organization, and international academic partners at a rural district hospital in Rwanda, engenders explicit priority setting dilemmas that may not be generalizable to other contexts. Resource availability for cancer care in Rwanda is also dynamic, and the specific dilemmas discussed by our participants (e.g., radiotherapy prioritization) have already evolved since our study period ended. In addition, although our study demonstrates moral distress and resilience strategies among clinicians, the relationship to burnout was not well characterized. Further research should quantify moral distress and burnout using validated measures [34, 35] and implement and evaluate interventions. Finally, although expertise from LMICs can be leveraged for guidance as oncology providers in HICs face resource constraints and inequities, significant differences across various contexts warrant dedicated attention. We encourage future research on the contribution of explicit and implicit priority setting to moral distress and burnout among oncology clinicians in HICs as well, particularly in settings where patient care and outcomes are shaped by structural inequalities.

CONCLUSION

This study adds to the current literature an in-depth analysis of how resource constraints and inequities drive moral distress among oncology clinicians in a low-resource setting. Although the experiences of oncology clinicians in Rwanda cannot be directly compared with those of oncologists practicing in other settings, their insights and resilience strategies can be leveraged to guide solutions for the entire oncology community.

AUTHOR CONTRIBUTIONS

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DISCLOSURES

The authors indicated no financial relationships.

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