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Citation

Samuels, A., Atikasari, H., & Lemos Dekker, N. (2025). Sociocultural dimensions of community-based palliative care in Brazil and Indonesia: an ethnographic study. *Health And Social Care In The Community, 2025*. doi:10.1155/hsc/4624886

Wiley
Health & Social Care in the Community
Volume 2025, Article ID 4624886, 7 pages
https://doi.org/10.1155/hsc/4624886

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Research Article

Sociocultural Dimensions of Community-Based Palliative Care in Brazil and Indonesia: An Ethnographic Study

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Received 6 March 2025; Revised 3 December 2025; Accepted 13 December 2025

Guest Editor: Qing-Wei Chen

Background: Palliative care services are increasingly implemented in diverse sociocultural settings around the world.
Aim: Our ethnographic project aimed to explore the sociocultural and organizational dimensions of community-based palliative care in Brazil and Indonesia.
Methods: We used ethnographic research methods to study local models of palliative care provision in Brazil and Indonesia. These countries were chosen because of similarities in stages of palliative care service development and yet differences in healthcare organization and dominant religion. After scoping initiatives, in each country, one thriving community-based initiative was selected for an in-depth case study through semistructured interviews and participant observation. Thematic analysis was first done for the individual cases and then compared across cases in team meetings.
Results: The case studies of community-based initiatives reveal (1) how local values are included in the development and practice of palliative care; (2) how these initiatives build on existing local health care structures; and (3) how local palliative care workers introduce the term "palliative care" with sensitivity to the local cultural context.
Conclusion: As palliative care services are implemented in various sociocultural settings, a better understanding of successful community-based models for palliative care provision is needed to adapt services to local contexts.

1. Introduction

Palliative care services are increasingly implemented in a wide range of socioculturally diverse settings around the world. Following successful early initiatives, "community-based" palliative care has gained attention over the past decade. The report of the Lancet Commission on Palliative Care, for example, signals an "essential role" for community health workers as part of its proposed Essential Package for palliative care [1]. The Global Atlas on Palliative Care highlights a number of diverse community-based palliative care models [2]. The 2018 WHO declaration of Astana encourages integration of palliative care in primary healthcare and thereby helps to bring further attention to community-based palliative care [3, 4]. Studies of community-based palliative care initiatives point at the importance of adapting palliative care services to local contexts [5]. Until now, however, there have been very few long-term empirical studies of bottom-up community-based palliative care initiatives in lower- and middle-income countries (LMICs) [6]. Little is known about the sociocultural and institutional dimensions that need to be taken into account when analyzing, supporting, and potentially scaling community-based palliative care initiatives as part of, or alongside, national policy on palliative care. The aim of our study is to contribute to filling this gap by identifying sociocultural and local institutional dimensions of community-based palliative care initiatives.

Scholars have noted that despite being increasingly a global health concern [7], palliative care research remains overwhelmingly focused on the Global North, indicating a need for increased understanding of Global South perspectives and priorities [8–12]. Existing studies of community-based palliative care in LMIC suggest a broader model of palliative care responding to complex needs, including social and economic assistance, food packages, and care for patients who do not suffer from life-threatening illness [6, 13, 14]. It is pointed out that in evaluating such efforts, it is critical to attend to how palliative care services are developed in relation to local values [4]. Given that local values and power relations influence the success of community-based interventions, implementing a community-based palliative care model in a new setting may involve substantial translational work [15]. Moreover, class and gender inequalities, social tensions, and power relations may significantly shape the possibilities of developing community-based palliative care [5, 16, 17]. Importantly, the extent of community engagement may differ significantly between different models [18].

Given the large variety of palliative care practices and sociocultural variety in approaches to illness, care, and dying, scholars have called for recognizing the plurality and heterogeneity of palliative care around the world, in contrast to global standardization [4, 19, 20]. Taking a postcolonial perspective, it is urgent to correct the Global-North centeredness of palliative care studies that tends to reiterate the predominance of Global North bioethical frameworks and values [12, 21, 22]. It also entails decolonizing pain relief policies in the Global South [23]. The attention to cultural diversity and to the wide range of end-of-life care practices existing prior to and beyond European-centered professional palliative care is further needed to decolonize insights in global palliative care [24]. Crucially, taking the role of culture and social and historical situatedness seriously goes beyond the description of a wide range of palliative care practices and models and acknowledges that Global South developments contribute theoretical insights to knowledge about global palliative care. It includes focused attention to family-centered and community-based initiatives in order to develop equitable global palliative care [25].

This study responds to limitations of the existing literature regarding the variety of community-based palliative care initiatives, particularly in the Global South, and the very limited theorization of the ways in which sociocultural dimensions shape community-based palliative care. The research objectives and comparative design of long-term ethnographic research are inspired by a postcolonial perspective that inquires into global power relations and does not take for granted a linear narrative of development in which standardized models of care are developed in the Global North to then be implemented in the Global South. Instead, it underscores that the call for decolonizing end-of-life care demands a "holistic approach that respects local culture and context to ensure that care systems are equitable and responsive to diverse needs" [25] and requires "plural imaginaries for end of life care" [22]. By studying and comparing two community-based palliative care initiatives in Brazil and Indonesia, this study contributes to understanding the sociocultural dimensions of palliative care in each case and the variability of community-based palliative care globally.

2. Methodology

This qualitative research study draws on a larger comparative ethnographic research project on the globalization of palliative care [26]. For this project, H.A. conducted eight months of ethnographic research in Jakarta, Indonesia, between February 2022 and January 2023 and N.L.D. conducted six months of ethnographic research in a middle-sized town in the South of Brazil between November 2021 and October 2024. Both researchers are nationals of the case study countries and native speakers of the local languages. After scoping the field, they each—in coordination with the other authors—selected one community-based initiative to study in depth, in addition to doing research in a hospital setting and with individual patients. This article draws on the findings from the studies of the community-based palliative care services.

2.1. Research Sites. Neither Brazil nor Indonesia has large-scale institutionally coordinated community-based palliative care services. Building on the calls for decolonizing end of life care and its knowledge production, we purposefully selected two initiatives based on the criterion of bottom-up development in relation to local needs, values, and practices. In both cases, the services were only partially integrated in the larger healthcare system. The two countries were selected based on relative stage of development of palliative care services, socioeconomic and historical situation, and religious diversity.

In Brazil, research was conducted at a community-based palliative care center in a middle-sized town. The center had been in development for approximately 5 years. At the center, local residents suffering from chronic and life-limiting illness could access a range of services, including medical treatment as well as physiotherapy, psychological services, and occupational therapy. The center employed both professional staff and volunteers.

In Indonesia, research was conducted at a community-based palliative care service in the capital, Jakarta. This program covered a group of urban neighborhoods. Research focused on a group of 13 volunteers (called *kader paliatif*), who visited neighbors suffering from life-limiting illnesses on a regular basis. Their activities ranged from checking in on the situation of the neighbor, providing a listening ear, and helping out in the household, to small physical care tasks, liaising with health care services, and helping with postdeath rituals and funeral arrangements. The program had been running since 2015. The volunteers received training from a national NGO.

2.2. Methods. In each country, the researchers used participant observation as the main method for ethnographic data collection. In Brazil, this entailed observing interactions at the community-based palliative care center, including consultations with physicians and social workers as well as daily occupational activities such as gardening and handicrafts. In Indonesia, this entailed shadowing volunteers on their visits to ill neighbors and participating in the regular volunteer social gatherings. In ethnographic research, it is commonly accepted that the researcher influences the situation observed through their participation [27]. The researchers recorded detailed written field notes of the observations and kept a reflexive journal, allowing for reflection on their role in the situations studied.

Informal and semistructured interviews were conducted in each site with a range of stakeholders, including professional healthcare workers, volunteers, and patients at the palliative care center in Brazil and volunteers, NGO workers, and palliative care activists related to the community-based program in Indonesia. Recorded interviews were transcribed. Handwritten interview notes were typed out directly after the interview. Interviews focused on the institutional dimensions of the program, experiences of care, and the social and cultural dimensions of palliative care provision. All interviews in Brazil were conducted in Portuguese, and all interviews in Indonesia were conducted in Indonesian.

2.3. Analysis. Following principles of grounded theory analysis, analysis was conducted iteratively in the interchange between data collection, analysis, and theory [28]. Data analysis commenced during fieldwork, when researchers started to note emerging themes of analysis. First, in between fieldwork periods and again after fieldwork, the researchers who conducted the research read through the data and categorized notes and participants' descriptions on sociocultural dimensions of palliative care in their respective settings. Second, three overarching themes were distinguished in multiple team meetings with all authors. We revisited the data as themes were developed. Findings have also been discussed with selected participants in both countries, among others, during the creation of postfieldwork outreach products, which included a photo exhibition in Brazil and a documentary film in Indonesia.

2.4. Ethics. In Brazil, written ethical permission was obtained from the community-based palliative care center where the research was conducted (date: 27 June 2023). In Indonesia, written ethical permission was obtained from the Research and Community Engagement Ethical Committee of the Faculty of Public Health of the University of Indonesia (Nr. Ket-24/UN2.F10.D11/PPM.00.02/2022). Because of the sensitivity of the topic of palliative care in the settings we studied, all participants have provided verbal rather than written informed consent to be included in the study, as is common in ethnographic research [29]. Participants were ensured of confidentiality and informed that their participation was voluntary and that they could withdraw from the study at any time. Ethical clearance for the project has also been obtained from the European Research Council Executive Agency that funded the project (Nr. (2019)7024593) and the Ethics Review Committee of the Social Sciences at Leiden University (date: 15 July 2020), where the project was hosted.

3. Findings

We identified three sociocultural and organizational dimensions that shaped the local community-based palliative care initiatives in Brazil and Indonesia.

3.1. Global Models and Local Values Shape Palliative Care Services. In both community-based initiatives, the development and implementation of palliative care services were inspired by international practices of palliative care. In Indonesia, the community-based volunteers received a series of trainings and coordination from healthcare workers at a national NGO. The trainers were Indonesian physicians and nurses who had themselves received palliative care training in places like Singapore, the United Kingdom, and Australia. They regularly referred to internationally shared palliative care principles and emphasized that palliative care is not only about physical illness but also psychosocial and spiritual care. In Brazil, N.L.D. observed that palliative care staff in the center often referred to the work of Cicely Saunders, who is commonly considered to be one of the founders of the modern palliative care and hospice movement, when introducing palliative care in official presentations during courses and events and one-on-one interactions. One of the rooms in the center was even named after Cicely Saunders. The values and principles developed in the early days of palliative care in the United Kingdom and the United States formed an explicit influence on the mission and activities of the center.

At the same time, in both initiatives, palliative care services were adapted to local needs and values. For example, in Brazil, N.L.D. observed that the social worker often filled a bag with food and basic provisions from a fully stocked gray metal cabinet, for patients who indicated they were struggling to get by. As one physician explained, "We are talking about therapy and dignity, but often we do not even know if a family has rice and beans to put on the table. This is unfortunately inherent to the social inequalities in Brazil." Besides this form of subsistence support the palliative care center also offered legal advice, which is important in the Brazilian context where accessing healthcare may require legal action. Moreover, because of the broad range of services offered, including physiotherapy, holistic services such as reiki and acupuncture, and occupational therapy, the center catered to a broad range of patients with temporary and chronic conditions beyond life-limiting illness.

In Indonesia, palliative care provision by the community-based volunteers was generally practiced with reference to spiritual language and by including Islamic religious care. For example, patients sometimes asked volunteers to pray together with them, to recite for them from the Quran or to arrange a Quran recitation session with neighbors and family. H.A. observed this directly when one day, the volunteers invited her to participate in a Quran recitation session at a patient's house. In reflecting on this practice, one volunteer called her work a religious calling. Another explained that her volunteer work was a form of worship (*ibadah*), saying that it was "[spiritually] important for humans to be useful to other people." In both Indonesia and Brazil, local values and needs of the community such as spiritual care, and socioeconomic and legal assistance form an important part of community-based palliative care.

3.2. Integration With Local Health Infrastructures. Both community-based initiatives that we studied made use of existing local health infrastructures to some extent. While integration in local health structures provided advantages, participants also expressed the importance of the values that they had developed in a bottom-up way.

In Brazil, the community-based palliative care center was structured as a primary healthcare center (UBS) similar to other centers in the region, which enabled access to government financing and equipment. However, rather than initiated by the government, the development of this center was initiated by dedicated healthcare professionals. It was unique in profiling itself as a palliative care center and initially struggled to obtain a suitable space, which the healthcare providers ended up constructing largely by themselves. The professionals and volunteers at this center participated actively in a national lobby for palliative care policies, which were approved in 2024. As a result, they expected improved resources for care provision and the training of additional staff in the coming years. They have thereby managed to both gain recognition and institutional support for their work and keep their mission focused on palliative care rather than becoming a more general health clinic, which is more common in the region.

The palliative care volunteers in Indonesia called themselves *kader* and thereby replicated a structure of local health volunteers (called *kader*) that exists across the country but not yet for palliative care. The kinds of activities they conducted by visiting neighbors to give advice and help connect them to health services were also similar to other *kader* volunteer groups. H.A. observed many such activities. For example, one afternoon, H.A. joined a 55-year-old palliative care volunteer who visited a neighbor who had recently been discharged from the hospital after breast cancer treatment. A few days later, H.A. visited the same patient with the same volunteer, this time together with nurses and doctors from an NGO, who conducted a medical check, cleaned the wound, and gave free incontinence pads and milk powder.

While such activities of visiting patients and connecting them to local health infrastructures where similar to other local health volunteers (such as Mother and Child health *kader* or Dengue Prevention *kader*), unlike the others, the *kader paliatif* were not formally recognized, nor directed through governmental health care structures, though they did receive training and coordination from a national NGO. The palliative care volunteers were also not eligible for any financial assistance, for example, for their transportation expenses and, therefore, worked on a fully voluntary basis, often with a religious motivation. The volunteers we spoke to, however, were ambivalent about further integration in the official healthcare structure. They welcomed further recognition of their work but were frustrated when (paid) healthcare workers expected them to deliver data on their activities and write reports. Furthermore, some of them pointed out that they did their volunteer work for religious reasons and that it was more spiritually valuable if done without any compensation. As one of them asked rhetorically, "At the moment, we are doing our palliative care work voluntarily for religious worship, but what if it will be professionalized and not voluntary anymore?" She thereby implied that professionalization might make their work less spiritually valuable. In this way, both in Indonesia and Brazil, palliative care professionals worked within as well as outside existing healthcare structures in order to develop their community palliative care practices.

3.3. Sensitivity and Shaping Palliative Care Terminology. In both sites, we noted sensitivity of the use of the term "palliative care." In both study locations, palliative care was initially not a well-known concept to local residents. Local residents sometimes had negative associations with the term palliative care, interpreting this form of care as only connected to the end of life. Palliative care professionals and volunteers carefully used the concept of palliative care according to specific local situations and contexts.

In the palliative care center in Brazil, professionals and volunteers actively tried to create more awareness of palliative care by repeatedly and patiently introducing the term to local residents. They took care to particularly emphasize that palliative care focused on quality of life and wellbeing rather than (only) on the process of dying. One patient, for example, explained that she learned about palliative care when she started visiting the center, and that for her, "palliative care is quality of life, it is not only the illness, it is everything, it is the whole human being." These efforts to create more local awareness of palliative care were also related to broader national efforts to gain recognition for palliative care that the center engaged in.

In Indonesia, palliative care volunteers said that people might be scared when hearing the term palliative care. Some of them told us that they would, therefore, introduce themselves to the patients as "just a neighbor" visiting and helping with advice. One participant said, "When I visit my neighbors, I introduce myself as 'neighborhood volunteer' (*kader kelurahan*), not as palliative care volunteer. Using the term palliative care will make the visit more complicated. People are not familiar with this term." This finding in the community-based program aligns with our observations in medical services in Indonesia, where palliative care workers introduce the concept of palliative care very carefully and usually speak only implicitly about death and dying.

4. Discussion

In this article, we have identified three sociocultural and organizational dimensions of community-based palliative care initiatives in Brazil and Indonesia. Our findings resonate with previous studies that point out the need for flexibility in community-based palliative care, in order to develop services in accordance with local values and needs

[6, 13–15]. While bottom-up developed community-based palliative care initiatives may be inspired and shaped by international discourses and training on palliative care, equal attention needs to be paid to the ways in which these initiatives develop their own interpretation of palliative care provision according to local needs and values [20]. Our finding that community-based palliative care in the initiatives in Brazil and Indonesia included care for people with non–life-threatening illnesses, food packages, and legal support (Brazil) and religious support and funerary assistance (Indonesia) underscore that community-based palliative care in LMICs may include broader social, economic, and religious support than elsewhere [6, 13, 30]. These findings form ethnographic evidence of the ways in which sociocultural values and economic dimensions shape what palliative care becomes in practice.

In setting up their initiatives, both the center in Brazil and the Indonesian *kader* volunteers built on existing organizational structures (namely, a primary healthcare center and volunteer structure, respectively) that were already well established in their local contexts. Community-based palliative care initiatives may benefit from integration in existing public health structures [31–33]. At the same time, they may experience a tension between a community's wish for ownership and voice on the one hand and centralized healthcare system coordination on the other hand [5]. The palliative care center professionals that we studied in Brazil managed to successfully lobby for recognition of palliative care and integration of the center in the larger healthcare structure, without losing the specific vision and focus on palliative care that the center had developed over the years. In Indonesia, palliative care volunteers worried that the spiritual value of their work might be lost with further bureaucratization and financial compensation, while at the same time, they valued the recognition that further professionalization might bring. The various ways in which communities negotiate tensions between local ownership and more centralized coordination of community-based palliative care are in need of further research.

In many parts of the world, serious illness and dying are sensitive topics and people may rather use implicit language to discuss these topics [16, 34–36]. Palliative care professionals and volunteers in our study expressed the importance of careful introduction of palliative care to the communities in which they worked. Some used different concepts than "palliative care" to communicate about their activities. This resonates with practices elsewhere. For example, in his work on palliative care provision in Rwanda, physician Ntizimira notes how he rather talks about "comfort" and "quality of life" than using the word "palliative care" which may not be familiar to patients and families [37]. Laabar et al. observe in Bhutan that "Many participants stated that currently, the phrase 'palliative care' does not exist in Bhutanese clinical practice but acknowledged the need for help in providing care to dying patients." [38]. This was similar to our finding in Indonesia, where community-based palliative care volunteers avoided using the term when speaking with patients, due to the sensitivity of discussing the end of life. As we observed in Brazil, another strategy for careful use of terminology in community-based palliative care can be attention to explaining the term "palliative care" to create broader awareness. In using this strategy, the professionals and palliative care volunteers in Brazil carefully shifted the focus to wellbeing, away from dying. The need to increase awareness of the scope of palliative care is a common theme in global palliative care [1, 39]. The variability in the use and interpretation of the term "palliative care" and the ways in which community-based palliative care workers respond to this point to the relative flexibility of the concept and the multiplicity of ways in which palliative care practices are given shape in different parts of the world.

As experience-near accounts of Global South community–based palliative care initiatives are still limited [6], our study underscores the need for research on Global South community–based palliative care. Values and needs for palliative care in communities in LMIC may be different from those in the Global North and, therefore, caution should be applied to balance Global North–based community palliative care with Global South perspectives [8, 11, 12]. Taking a postcolonial perspective as its starting point, our study contributes to questioning the universality of models of palliative care provision, by showing how community-based care may take different shapes in diverse contexts. Applying this perspective demands that scholars take into account both cultural dimensions of care and the unequal global and local distribution of needs, resources, and institutional support. It warrants taking seriously the range of palliative and end of life care practices that are based in communities and families [25].

Given that this was an in-depth ethnographic study, which focused on only one community-based palliative care center in Brazil and a volunteer program in one community in Indonesia, the findings are not representative of the sociocultural dimensions of other initiatives in other social and geographic settings. Moreover, professionals and volunteers were relatively better represented in the interviews and observations than patients. Other community-based palliative care initiatives around the world need to be studied for comparison. Despite these limitations, our findings show sociocultural and organizational dimensions of community-based palliative care that resonate with the limited body of existing literature on community-based palliative care in the Global South. More research is needed to identify additional sociocultural and organizational dimensions and explore the diversity of palliative care practices around the world.

5. Conclusion

Palliative care services are implemented in a wide variety of sociocultural settings. This ethnographic study of two bottom-up-initiatedcommunity-based palliative care services in Brazil and Indonesia shows how local sociocultural and organizational dimensions shape what palliative care becomes in practice in diverse settings. It reveals three sociocultural and organizational dimensions of the studied initiatives that are important for locally suitable palliative care provision, namely, the balancing of global palliative care models and discourse with local values and needs; the balancing of integration in existing healthcare structures and keeping the initiative's independence and vision; and sensitivity in use and explanation of palliative care terminology. Future research on additional community-based palliative care initiatives in the Global South is needed to understand the diversity of palliative care practices and to enable adaptation of services to local contexts.

Data Availability Statement

The data that support the findings of this study are not publicly available due to privacy or ethical restrictions.

Disclosure

Parts of the abstract of this paper have been published before as part of the EAPC2023 Abstract Book [40] and are reproduced with permission.

Conflicts of Interest

The authors declare no conflicts of interest.

Funding

This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement no. 851437).

Acknowledgments

We thank Shajeela Shawkat for inspiring conversations on this project, and we thank two anonymous reviewers for their helpful suggestions.

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