

More information
on the project
and publications



Globalizing Palliative Care

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How do global palliative care discourses, policies and practices translate to various cultural contexts? Based on ethnographic research in Brazil, India and Indonesia, in the Globalizing Palliative Care ethnographic research project we found that:

- When developed in new settings, palliative care services often combine insights from international palliative care discourses with local values and concepts.
- The term palliative care may be sensitive in diverse cultural settings. Palliative care professionals often introduce the term carefully or use alternative concepts.
- Ethnographically following end-of-life care trajectories offers unique insight into how patients and caregivers navigate formal and informal care, how they encounter barriers to access specialist care, and how silence shapes end-of-life care experiences.
- Having regular moments of ethical debrief and team conversations on ethics before during, and after ethnographic fieldwork is crucially important to conducting ethnographies of care for people with advanced illness and at the end of life.



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Within Indonesia's archipelago, **travelling for treatment of advanced illnesses** often results in financial precarity and considerable psychological and emotional challenges for individuals who live far from referral centers.

Palliative care takes multiple forms across hospital and community settings, and is **socially, religiously, and culturally grounded.**



Navigating advanced illness within a growing treatment and palliative care system

Existing community healthcare structures offer **great potential to improve home-based care** for patients with advanced illness.

To communicate about end-of-life care with patients and family members, palliative care professionals and volunteers often rely on implicit communication strategies.

Ethnographically studying **care trajectories of patients with advanced illness and their families** provides insights into how care is shaped, practiced, and negotiated both within and beyond the hospital.

Research by Hanum Atikasari



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India
Bangalore



Orientation towards the future shapes everyday life. Possible futures are imagined unevenly, shaped by social relations, resources, and constraints. Life after injury is not oriented towards recovery alone, but towards futures that remain meaningful and possible.



Research by Syeda Shajeela Shawkat



Intimacy and touch are central sites where personhood is negotiated.

Touch is not only functional assistance; it is a relational practice through which intimacy, discomfort, humour, desire, and boundaries are remade.

Negotiating

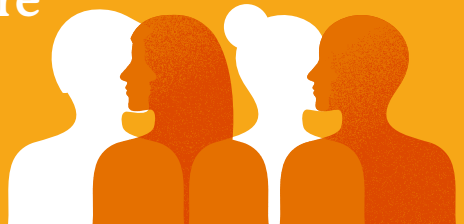
Continuously

Personhood

Spinal cord injury rehabilitation is primarily focused on improving physical functionality. This focus shapes how people come to understand themselves and their personhood.

Renegotiating personhood after spinal cord injury through everyday practices of care, intimacy, and orientations towards the future

Care is a relational process. It is shaped through everyday interactions, as emotions, boundaries, and responsibilities are continuously negotiated.



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Brazil



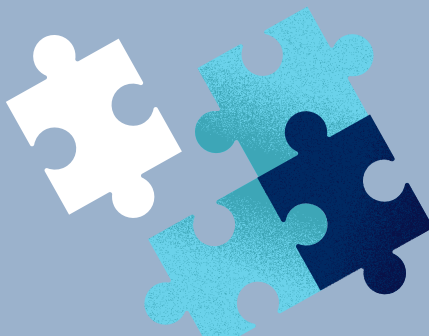
By involving the community in the activities of a palliative care center, it becomes a space for social participation that people visit as part of their everyday lives and where they can develop a sense of belonging.

The rapidly evolving social landscape of palliative care: how patients, families, and professionals shape the end of life



To obtain access to care, patients and families must **navigate between the public health care system, private health providers, and personal networks**, which become complementary in their care trajectory. This navigation requires substantial knowledge of medical conditions and systems.

Palliative care activism has been crucial to foster political support for palliative care in Brazil. Professionals from a wide range of disciplines have united, creating networks and sharing knowledge to increase its visibility and contributing to a shift in the cultural landscape of end-of-life care.



Research by Natashe Lemos Dekker



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