

Collective action frame and organizational field emergence in the context of palliative care in Kerala, India

ABSTRACT

With rapid rates of changes in demographics and lifestyle patterns across the world, provision of palliative care is emerging as a global public health concern. Palliative care is defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness". The most dominant form of organizing for the delivery of palliative care is the hospice-based approach, which relies on a professionally-trained group of doctors, nurses, social workers, and care-givers to provide care and support to patients and their families. Although the hospice movement has diffused across 156 countries, most nations continue to grapple with issues of access and affordability. Further, the challenge of end-of life care becomes multilayered and complex given cultural taboos, lack of awareness, myths within the medical fraternity, and the futile use of technology to prolong life.

Within this scenario, there is global recognition of the exemplary role of the volunteer-driven, community-based palliative care model that has developed in the state of Kerala in India. This context affords an ideal opportunity to gain insights into the complex processes of collective action that underpin organizational and institutional emergence. This dissertation encompasses two empirical studies that develop an account of why and how the palliative care field in Kerala emerged as a volunteer-driven, community based movement. Theoretically, we leverage the nascent, but growing body of research at the intersection of social movement theory and organizational theory.

The first empirical study traces the interpretive processes that underpinned the evolution of the palliative care movement in Kerala. Drawing upon literature on framing in social movements, this study illustrates the manner in which ordinary citizens made sense of a healthcare problem, engaged in mobilizing participation, and constructed new practices to address the challenges faced. Our findings suggest two key themes: First, frames that emerge at the grass-roots level, and in many occasions from bystanders, can become dominant frames of a movement. Second, frame alignment processes may be directed by non-elites towards the elites. These findings diverge from prior literature which emphasizes the roles of movement leaders and other key actors in framing issues and strategies.

The second empirical study examines the coordinated, collective dimension of agency in institutional emergence. We identify socio-structural and contextual mechanisms that govern the functioning of distributed actors in the emerging palliative care field. We propose a model that suggests interesting interactions between the convergent and divergent mechanisms that propel the development of new institutions. These findings emphasize the role of distributed agency in institutional change and contribute to filling existing gaps in our understanding of agency in institutional processes, organizational emergence, and the microfoundations of institutional theory.

Finally, the implications of these two studies for theory, methodology, policy and practice are discussed.