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Chapter 1

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The practices of palliative care and advance care planning as we currently know them in medicine have their cultural roots in the United Kingdom and the United States. Modern palliative care was developed in the 1960s and 70s in England, shaped by the work and activism of Dr. Cicely Saunders.[1] Scholars have noted how its holistic approach to the patient by interconnecting physical, social, spiritual, and psychological suffering is influenced by Anglo-Christian traditions of confession towards the end of life.[2] Advance Care Planning was developed in the United States with the aim of improving care at the end of life by discussing patient goals and wishes prior to a moment in which they may lack the capacity to decide. Although recent critiques point at the limited evidence for ACP's effectiveness[3] and its strong cultural emphasis on autonomy and self-determination that may not be suitable in diverse cultural settings,[4] the practice has also found widespread resonance and adaptation around the world.

So far, however, the overwhelming majority of studies on ACP have been conducted in the Global North. This is currently changing. Globally, scholars, policymakers, and health care workers develop approaches and practices that fit cultural ways of approaching illness, death, and dying that are quite different from those encountered by Cicely Saunders, and later developed in hospice and palliative care approaches, as well as ACP. This leads to increasing insight into cultural diversity and ACP,[5] new

models for ACP in specific regions,[6] and the growing global recognition that there may be "multiple futures" for palliative care.[7]

The country-based reflections in this section add significantly to this emerging body of knowledge on ACP and cultural sensitivity, particularly in Asia. Before diving into these specific reflections, however, I will briefly reflect on scholarly approaches to the concepts of "culture" and "cultural diversity" when it comes to ACP. To do so, I borrow insights from discussions on culture in the social sciences, particularly sociology and anthropology.

Rethinking Culture

For most of the twentieth century, anthropologists and other social scientists saw culture as a specific set of customs, practices, rituals, language, and beliefs belonging to a specific group living in a specific geographical region. From the 1970s onwards, however, this notion of cultures as bounded wholes confined in place has been turned completely upside down.[8] Social scientists then started to increasingly recognize that people had always continuously been traveling and exchanging ideas and that power relations shaped interactions within and across societies. Even in the remotest villages, the socio-cultural experience of two given individuals might therefore not be entirely the same. "Culture" came to be seen as not a list of things or practices that universally applies to a given society or group and that can be described separately from actual behavior. Rather, to understand how culture shapes human behavior and interaction, it is more useful to look at the processes and practices through which individuals and collectives create and enact cultural differences or understandings — processes that always take place within structures of power.

The consequences of this move away from studying "a" culture as if separate from people's lived experiences and social inequalities and towards looking at diversity as a dynamic and interactive process that is continuously practiced and in flux, are many. We should note, for example, that it becomes impossible to speak of something like "the Indonesian culture" or "the Italian culture" because societies differ internally as much as they may differ from other societies.[8] A highly educated woman in Yogyakarta may in many ways have more in common with her counterpart in Milan than with a fisherman in Manado. This is a crucial insight for medicine, as it should caution against essentialization: a patient entering the consultation room may be related to a particular social group in society, yet this does not mean that this patient's treatment preferences necessarily align

with what the health care worker may presume about this socio-cultural or religious group.[9] At the same time, seeing cultural practice as a dynamic process has taught us to understand biomedical practice itself as cultural and varying across times and places.[10] "Culturally informed care," then, as Kleinman and Benson[9] have argued, starts less from clinicians' knowledge about a particular ethnic group and more from them asking patients "what matters most to them in the experience of illness and treatment."

Cultural Diversity and ACP

This brings us to the importance of studying culturally sensitive practices of Advance Care Planning. Social scientists have long studied end-of-life care as a cultural process,[11] and recent studies show a large variety of practices in approaching death, dying, and palliative care around the world, as well as within Asia.[12,13] Such cultural variation consists for example of the extent to which people value discussing death and dying, the mode and manner of communication about serious illness and the end of life, preferences for the place of death, and the role of social and family relations in the health care process. Given this variety, and the aforementioned "Western" cultural roots of palliative care and ACP, it should not be surprising that scholars and professionals are calling for culturally sensitive practices of ACP and palliative care[14,15] and multicultural research groups.[16] They point out how it is crucial to take diverse cultural contexts and practices into account when developing locally situated ACP.

Research on cultural aspects of ACP has mostly taken place in the Global North, where ACP and palliative care have been studied in relation to ethnic and other minorities. These studies yield interesting insights, for example pointing at the importance of cultural values and spirituality, as well as differences in possibilities for accessing palliative care.[17] However, until a few years ago, studies on cultural dimensions of ACP outside of Global North settings were relatively limited.

Perspectives from Asia and the Pacific

Recent publications about ACP in Asia have started to fill this lacunae, by studying cultural dimensions of ACP and palliative care in diverse national and local settings.[5,18–20] The chapters that follow further contribute to this important development. They highlight, for example how the sensitivity of

openly discussing the end of life in various Asian contexts has significant implications for ACP and the way it is adapted to work for patients and healthcare workers. In the case of Samoa, participants in a series of workshops on ACP pointed out the importance of the local value of *tausi matua*, which denotes the responsibility of family members to take care. The reliance on family members' care and decision-making is considered crucial to include in ACP implementation. Moreover, patients and family members may feel that discussing the end of life can evoke an earlier death, and health is mainly discussed within the family. These sensitivities appear crucial to be included in ACP development, as we will also see in the case of Singapore where family-centred patient care offers a promising alternative to discourses of autonomy and patient-centred care.

The case of Japan similarly shows how implicit rather than explicit communication is valued in many Asian Societies, and how family plays a crucial role in ACP. Patients' expressions of their wishes can be influenced by the cultural value of not being a burden on the family. As shown below, ACP implementation in Asia may therefore benefit from drawing on the concept of "relational autonomy", in which patients are considered as always embedded in a social network rather than singular individuals standing apart from their social relations. Yet, as the case of Japan also points out, practices of talking and not talking about dying are changing. Therefore it is crucial to keep inquiring into the patients' preferences rather than a priori assuming cultural values. This point is underscored in the case of Australia, where research emphasizes the importance of avoiding essentialist readings of preferences of cultural minority groups. Taken together, these cases not only reveal the need for creating culturally sensitive models for ACP in Asian societies, but also give important pointers for the factors to take into account in this process, including the sensitivity of discussing dying, preferences for implicit communication, the importance of the family in healthcare decision-making practices, and the cultural changes that create increasingly diverse preferences for discussing and planning care.

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