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Discussing dying in the diaspora: Attitudes towards advance care planning among first generation Dutch and Italian migrants in rural Australia

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ABSTRACT

Western cultural practices and values have largely shaped advance care planning (ACP) policies across the world. Low uptake of ACP among ethnic minority groups in Western countries has been interpreted with reference to cultural differences. This paper adopts a life-history approach to explore attitudes towards ACP among older, first-generation Dutch-Australian and Italian-Australian migrants. Thirty people participated in extended ethnographic interviews ($N = 17$) and group discussions ($N = 13$) during 2012. Transcripts were thematically analyzed and interpreted using a Foucauldian perspective on knowledge and power. Migration experiences, ongoing contact with the native country and participation in migrant community support networks influenced attitudes towards ACP. Dutch participants framed ACP discussions with reference to euthanasia, and adopted a more individualist approach to medical decision-making. Italian participants often spoke of familial roles and emphasized a family-based decision making style. The importance of migrant identity has been neglected in previous discussions of cultural factors influencing ACP uptake among ethnic minority groups. The unique migration experience should be considered alongside culturally appropriate approaches to decision-making, in order to ensure equitable access to ACP among migrant groups.

Introduction

Advance care planning (ACP) is a process of ongoing reflection and communication between patients, health professionals and family members, aimed at ensuring that medical decisions made on a patient's behalf are in line with their wishes (Sudore & Fried, 2010). This encompasses both informal discussions about a patient's values and beliefs, and the use of legally binding advance directive (AD) forms, which document specific treatment preferences and/or proxy medical decision-makers. These treatment preferences often specify a patient's desire for withdrawal or withholding of life-sustaining therapies (such as invasive ventilation) in the event of a terminal illness (Nishimura et al., 2007).

The process of ACP has been promoted as a means of upholding patient autonomy in end-of-life care (Bito et al., 2007). Western countries in which individual autonomy is highly valued have typically been the first to enact legislation supporting a patient's right to use AD forms to request the withdrawal or withholding of medical treatments (Gysels et al., 2012; Johnstone & Kanitsaki, 2009). In the United States the Patient Self Determination Act requires that patients be informed on admission of their right to use ADs and to refuse medical treatment (Galambos, 1998).

In Western Australia, legislation supporting ACP was enacted in 2010. The Advance Health Directive (AHD) allows a person to specify their consent or refusal of consent for future medical treatments (Department of Health WA, 2010). The Enduring Power of Guardianship form (EPG) enables a person to nominate a health care proxy to make health and lifestyle decisions on their behalf (Office of the Public Advocate WA, 2010). Research has shown that facilitated ACP can improve the quality of end-of-life care, resulting in benefits including improved patient satisfaction and reduced psychological morbidity among bereaved family members, without leading to increased mortality (Detering, Hancock, Reade, & Silvester, 2010).

While research suggests the utility of ACP in improving the quality of end-of-life care, consistent findings from the United States have shown that white Americans express more positive views towards ACP, and are more likely to complete AD forms, than are minority ethnic groups (Blackhall, Murphy, Frank, Michel, &

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Azen, 1995; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002; Werth, Blevins, Toussaint, & Durham, 2002). Comparative research across four European countries has shown lower rates of discussion about treatment preferences between patients and doctors, and lower rates of nominating proxy medical decision-makers, in southern-European (Italy, Spain), compared to northern-European (Belgium, Netherlands) countries (Evans et al., 2013). A number of authors have suggested cultural factors in explaining these discrepancies (Searight & Gafford, 2005; Werth et al., 2002).

Culture has been defined as "the values, beliefs and behaviors that a people hold in common, transmit across generations, and use to interpret experiences" (Perkins et al., 2002, p. 48). Of particular relevance to the topic of end-of-life care are the cultural constructs of individualism and familism. Individualism has been defined as the "socio-cultural beliefs and practices that encourage and legitimate the autonomy, equality, and dignity of the individual" (Greene, 2008, p. 117). Familism is defined as "a set of cultural values that produce strong feelings of attachment to, and identification with, individuals in the nuclear and extended family group" (Benedetti, Cohen, & Taylor, 2013, p. 42); and is characterized by a strong sense of obligation to family members, and defining one's own identity through relationships with family members (Almeida, Molnar, Kawachi, & Subramanian, 2009; Schwartz et al., 2010).

Searight and Gafford (2005) suggest that cultural factors, such as individualism and familism, impact on end-of-life care in three key domains; the communication of bad news, the locus of medical decision-making, and attitudes towards advance directives. Cultures in which individualism is prominent tend to follow an 'autonomy-control narrative' (Gordon & Paci, 1997), typically prioritizing 'truth-telling' in diagnosis and prognosis (J. A. Low et al., 2009). Full disclosure is seen as a means of enabling informed patients to take a central role in medical decision-making (Gordon & Paci, 1997; Rietjens, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2006). On the other hand, cultures in which familism is more prominent tend to follow a 'social-embeddedness narrative', in which autonomy is perceived as a burden (Gordon & Paci, 1997). This perspective emphasizes the potential for 'truth-telling' to be harmful to the patient (Blank, 2011), and tends to place a greater emphasis on family-based decision-making (Searight & Gafford, 2005; Werth et al., 2002). Attitudes towards advance directives vary across different countries, ranging from ideological support reflected in legislation, to an absence of any formal framework (Blank, 2011; Searight & Gafford, 2005). Support for advance directives is also motivated by different priorities; for example in Australia advance directives are thought to be consistent with the value of patient autonomy (Sinclair, Auret, & Burgess, 2013), while in Japan the benefits of advance directives are framed with reference to their potential to reduce burden on families in end-of-life care (Bito et al., 2007).

Cultural factors undoubtedly contribute to attitudes towards ACP. However, it is important to recognize that observed differences in response to ACP between ethnic minorities and the dominant culture will also reflect power imbalances between groups. Those who have experienced disadvantage on the basis of their membership of an ethnic group may understandably adopt an attitude of mistrust towards a range of institutions; indeed ethnic minority groups typically report less trust of health services (Johnson, Kuchibhatla, & Tulsky, 2008). Johnstone and Kanitsaki (2009) point out that ACP carries the implicit understanding that the 'freedom' allowed to patients is that of forgoing, rather than increasing, medical care. We argue that reactions of mistrust towards ACP do not qualify as cultural traits just because they are associated with membership of a particular ethnic or cultural group. Rather, mistrust of ACP amongst ethnic minorities should be understood within the context of embedded relations of power and the sensitivities engendered by individual and communal histories of being 'other'.

The work of Michel Foucault, with its emphasis on notions of governmentality, biopower and control, provides a useful frame for analyzing the experiences of ethnic minorities in societies such as Australia. In regards to health (Petersen, 1997), education (Dwyer, 1995) and other institutional power structures, minorities have had to simultaneously accommodate and resist pressures to fit in, to be the 'docile bodies' preferred by the modern nation state (Foucault, 1995). Within the health sphere, Foucault's concept of 'biopower' has the greatest relevance to understanding the concerns of migrant communities surrounding ACP. Biopower entails the "explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations" (Foucault, 1998, p. 140), though perhaps it is more usefully understood as the ways in which the nation state co-opts citizens into managing their health, and that of others, in the interest of the state. This is particularly true given the history of migration to Australia, where the medicalization of ethnic difference was entrenched in official discourse. The controversial 'White Australia' policy, predicated on the grounds of British physical and mental superiority, and the belief that acceptance of non-British migrants would result in the introduction of disease and, in the event of intermarriage, genetic 'weakening' of the Australian population, was only slowly dismantled (Bashford, 2002). Indeed until well after World War II, northern-European migrants were preferred over southern Europeans, who were in turn preferred to migrants of non-European ethnicities (Peters, 2001). For migrants arriving during the immediate post-war period, the legacies of this rhetoric, alongside their knowledge of the monstrous exercise of biopower during the Holocaust and attendant atrocities, had profound implications for trust in government and associated institutions and for their own self-perception (e.g. Hodges & Schmidt, 2009).

Today, Australia is a culturally diverse nation, with over seven million migrants, from more than 270 ancestral groups, having arrived since World War II (Australian Multicultural Council, 2013). A significant and growing proportion of Australian health service consumers come from culturally and linguistically diverse (CaLD) backgrounds. The growing reliance on internationally trained medical professionals, particularly to service rural areas, has further reduced cultural concordance between patients and doctors (Spike, 2006). It is likely that a growing number of discussions about ACP are taking place in the context of cross-cultural doctor-patient interactions, signaling the need for a coherent body of research, which can guide best practice in this area.

Dutch and Italian migrants arrived in Australia in large numbers during the 25 years following World War II (Ugolini, 1992). Many settled in rural areas (Dade-Smith, 2007), and the majority of these first generation migrants are now approaching old age (Office of Multicultural Interests, 2006). Of the 5.3 million overseas born residents in Australia, just over 1 million are over the age of 65, and of these 3.5% and 10.8% are Dutch and Italian born, respectively (Australian Bureau of Statistics, 2013). Given the marked differences in approaches to end-of-life care across countries in Europe (Evans et al., 2013; Gysels et al., 2012; Menaca et al., 2012), and the lasting influence of the native culture on migrant attitudes towards ACP (Bito et al., 2007), it is likely that Dutch-Australian and Italian-Australian migrants will maintain different attitudes to ACP. The Netherlands is characterized by legislation supporting advance directives and euthanasia, suggesting relatively open attitudes regarding patient preferences in end-of-life care (Rietjens et al., 2006). Italy does not have clear policies relating to end-of-life care; ADs and next-of-kin are not legally recognized in the event of a patient's incompetency (Maggiore & Antonelli, 2005; Menaca et al., 2012; Servillo & Striano, 2008).