



Forecasting and foreclosing futures: The temporal dissonance of advance care directives

Tanya Zivkovic

Department of Sociology, Criminology and Gender Studies, School of Social Sciences, Napier Building, University of Adelaide, Adelaide, South Australia, 5005, Australia



ARTICLE INFO

Keywords:

Advance care directives
Temporality
Choice
Cross-cultural
Decision-making

ABSTRACT

Advance care directives situate persons as rational and self-determining actors who can make anticipatory plans about their futures. This paper critically examines how people interpret individual and future-oriented approaches to medical decision-making with limited access to information and knowledge, and reduced opportunities to prepare and document their care preferences. Based on ethnographic research with Asian migrant families living in Adelaide, South Australia (August 2015–July 2018), it reveals a discord between planning for a finite future and the contingencies and continuities of social life. It unsettles the detached reasoning that is privileged in end-of-life decision-making and reveals limitations to “do-it-yourself” approaches to advance care directives which, it will be argued, not only forecasts potential futures but also forecloses them. Taking Derrida’s critique of death and decision-making as a point of departure, it develops the concept of temporal dissonance as a theoretical framework to articulate the tensions that are constituted in advance care directives. The paper suggests that attention to temporal incongruities may help to shed light on the many complex interpretations of advance care directives and the difficulties of promoting them in diverse contexts.

1. Introduction

Central to advance care directives (ACDs) is the assumption that individuals can anticipate and plan for the trajectories of their lives and deaths through formal written statements about their preferences or the appointment of a substitute decision maker. This pre-emptive approach to ageing, illness and death emphasises the autonomy and self-determination of consenting adults to make and document decisions about their futures. They form part of a process of advance care planning (ACP), a broad term used to describe multiple ways (including informal conversations, recording wishes in writing, appointing a substitute decision maker) of anticipating and responding to future care needs. In a systematic review of ACP, Brinkman-Stoppelenburg (2014) caution against the use of ACDs in isolation from broader ACP processes that may increase the quality of care at the end of life. Yet, at the same time, there is a growing critique against ACP policy and practice, for its temporal orientation to an uncertain future (Borgstrom, 2015a; Perkins, 2007; Sudore and Fried, 2010), the prioritisation of the physical document over relational contexts of care (Borgstrom, 2015b; Johnstone and Kanitsaki, 1999), and embedded assumptions that all individuals want and can have a hand in writing their futures (Searight and Gafford, 2005a).

ACP processes and documents were developed in the US and most research in this area has focused on Anglo and European communities,

however researchers are increasingly examining the extent to which they may enable (or pose challenges to) the delivery of appropriate and sensitive care in culturally diverse populations (Menon et al., 2018). Studies show that the complexities of health and end-of-life care may be compounded in culturally diverse and interfaith communities if their values do not reflect those of the dominant culture (Kagawa-Singer and Blackhall, 2001). Cultural preferences for non-disclosure of prognosis (Bowman and Singer, 2001; Candib, 2002; Fan and Li, 2004; McGrath et al., 2001; Searight and Gafford, 2005a, 2015b); religious, faith-based considerations (Bullock, 2006; Doorenbos and Nies, 2003; Johnson et al., 2005); the experience of migration (Sinclair et al., 2014), collective and familial models of decision-making (Bowman and Singer, 2001; Candib, 2002; Fan, 1997; Frey et al., 2014; Kwak and Haley, 2005; McGrath et al., 2001; Yang, 2015); diverse explanatory systems concerning the cause and treatment of illness, personhood and ways of understanding death and dying (Lock, 2002), power inequities and mistrust of health care systems (Bullock, 2006; Candib, 2002; Johnstone and Kanitsaki, 2009; Searight and Gafford, 2005b; Sinclair et al., 2014), and limited access to culturally sensitive (in-language) health care and services (Searight and Gafford, 2005a, 2005b), can challenge notions of individual decision-making, disrupting the values of autonomy and personal responsibility on which ACP and ACDs are hinged.

Social and medical scientists have critiqued anticipatory approaches

E-mail address: tanya.zivkovic@adelaide.edu.au.

<https://doi.org/10.1016/j.socscimed.2018.08.035>

Received 24 April 2018; Received in revised form 25 August 2018; Accepted 28 August 2018

Available online 29 August 2018

0277-9536/ © 2018 Elsevier Ltd. All rights reserved.

to the future for overlooking the intersections of ethnicity, religion, gender and class that shape bodies and the horizons of opportunity along which health “choices” are available and decisions made (Cohen et al., 2010; Perkins, 2007; Warin et al., 2015). Power to calculate the future – or to “choreograph” one’s death (Perkins, 2007, p. 54) – requires “first of all having a grasp on the present” (Bourdieu, 2000, p. 221). Recent social analyses on precarity and disadvantage challenge the belief that the future is always imaginable (Allison, 2013) or in reach (Berlant, 2006). Yet health policy and practice urges individuals, despite socio-economic constraints or cultural preferences, to plan ahead; to control the vicissitudes of ageing and the unpredictability of dying. In a neoliberal climate, ageing, disease and death become risks to be anticipated, managed and controlled (Giddens, 1991).

Taking as its point of departure the South Australian DIY (do-it-yourself) ACD, this paper asks the following questions: to what extent can we all – and in equal measure – know and grasp the future? Do we all want or have the capacity to make rational, independent and calculative care decisions? Can we plan for the final stages of our lives? As Mol (2008) makes clear in her monograph on care and choice in a diabetes clinic, we never have all the facts on the table before decisions are made. Following analyses on choice and decision-making (Mol, 2008; Borgstrom and Walter, 2015), this paper calls into question the temporal orientation to the future and detached reasoning inscribed in ACDs, and attends to the uncertainty and relationality that characterises anticipatory decision-making. Drawing on Derrida’s deconstructive approach to death and decisions, it outlines migrant responses to ACDs in the face of an unknown and uncertain future. The instant of a decision, for Derrida (1995), is beyond reason or fact because *we cannot advance beyond the present* moment in time. Following Kierkegaard, Derrida proposes that the decision is thus a moment of madness, “a duration that cannot be grasped: something one can neither stabilize, establish, *grasp [prendre], apprehend, or comprehend*” (1995, p. 65). Extending the perpetuity of the now to death itself, Derrida (1993) underscored that death, like the future, is always yet to come. Death, for Derrida, cannot be seized. “It remains irreducible to presence or to presentation, it demands a temporality of the instant without ever constituting a present” (1995, p. 65). The irrevocable termination of one’s cognitive and sensory capacities precludes one’s personal experience of death. Death, as such, can never be an event in one’s life.

This paper will examine how this double-interminability of living and the now presents a temporal dissonance, inhibiting one’s capacity to plan for future medical treatments or prepare for the end of life. It will be argued that the conditions for choice or possibility that are presumed to exist in ACDs are simultaneously the conditions of impossibility. Extending Derrida, it will show how migrant interpretations of ACD not only destabilised the logic of forecasting uncertain futures (Perkins, 2007) but also revealed concerns that documenting decisions could constrict futures and limit the chance for continuing life.

2. “Do it yourself” advance care directives?

In Australia, as with many other countries, medical and technological advances are increasingly directed to care in the last 18 months of a person’s life, widening the prospect of prolonged, painful, expensive deaths that are emotionally burdensome to both the dying person and their families (Scott et al., 2013). As a result, there is an increased focus on the documentation of end-of-life care preferences to avoid medical treatments that may be considered unproductive, and thereby reduce the social and economic costs of dying. In the state of South Australia, where the highest proportion of Australia’s aged population live, the focus on how people die has led to legislative change in the area of anticipatory decision making. Taking the national lead in advance directives, the state government passed an Advance Care Directives Act in 2013 and then in 2014 launched the *Advance Care Directive Do-It-Yourself Kit* for individuals to document what care they would want if at a future time they were unable to communicate their preferences. It

asks people to consider what will matter most to them when they have “impaired decision-making capacity”, who they would want to make decisions for them when they are unable and any treatment options they would refuse. Although ACDs can apply at any stage of an adult’s life (once they are deemed to no longer have decision-making capacity), in policy and practice they are largely associated with end-of-life decision-making. In policy white papers ACP and their formal documentation in ACDs are frequently cited as a way to facilitate an idealised ‘good death’ (Green, 2008), and the 2014 Grattan Institute Report emphasises their importance in *Dying Well* (Swerissen and Duckett, 2014). In line with the *National Framework for Advance Care Directives* (2010), other jurisdictions have since enacted new legislation on ACDs, highlighting a national trend toward the implementation of ACDs in mainstream standard care. Positioned within a human rights approach to ageing and death, ACDs place emphasis on the right and responsibility of all Australians to document any refusals of medical treatment (Australian Human Rights Commission, 2012).

Against the tide of reforms and increasing publicity to “make your future health and life choices known” (Government of South Australia, 2017), many Australians experience low levels of health literacy and are not exposed to ACP processes or documents. In Australia, as in the UK and much of the US, uptake remains low, and despite the undercurrents of universality that flow through ACD discourse there is evidence to suggest that migrant populations and ethnic minorities are less likely to have an ACD or engage in ACP (Bradley et al., 2014; Bowman and Singer, 2001; Krakauer et al., 2002; Johnstone and Kanitsaki, 2009; Sinclair et al., 2014). However, while South Australian survey data indicates that Australian born residents are more likely to take up ACDs (Bradley et al., 2014), White et al.’s (2014) national telephone survey on the prevalence of advance directives reports that ethnically diverse Australians are no less likely to have one. In other recent Australian studies modified versions of ACP processes with in-language resources were found to be feasible and acceptable in some migrant communities (Detering et al., 2015; Yap et al., 2017).

Historically, Australia’s older overseas born residents have come mostly from the UK and Europe, and most ACP research and implementation in Australia has been undertaken in Anglo-European groups (Detering et al., 2010, 2015; Sinclair et al., 2014). Today, the demographics are rapidly changing and the main birthplaces for culturally and linguistically diverse migrants aged between 50 and 65 (apart from those born in Italy) are Asian countries (namely China, Vietnam, India, and the Philippines), reflecting increased ageing and migration of Asian groups to Australia since the White Australian Policy came to an end in 1973. Now, over 40 years later, the first wave of post-White Australia Asian migrants are approaching an age at which end-of-life issues increase in importance. Accordingly, the 2012 Senate inquiry into *Palliative Care in Australia* and the 2013 Health Performance Council report *Improving End of Life Care* called for increased recognition of diverse cultural needs and religious practices, with the latter report highlighting a “lack of awareness of taboo topics and social codes” around death and dying and stating that non-Anglo -European “family structures” and “religious practices are not well recognised”, and therefore inadequately accommodated (2013, p. 49).

Given the need for more nuanced and culturally sensitive approaches to care, ACDs have been viewed as a way to support individuals to make their own decisions in accord with diverse preferences. But as Australian and international studies have shown, notions of “individual autonomy” and “choice” reflect a neoliberal agenda that does not universally reflect health concerns across the life-course (Borgstrom and Walter, 2015; Wilson et al., 2014). Critiquing biomedical rationality (Good, 1994) and its emphasis on “choice”, Good (1986, p. 164) aligned medical models of decision-making with “false assumptions about the freedom of individuals to make voluntary decisions, thus reducing attention to overwhelming social constraints”. Indeed, recent Australian scholarship on the role of ACP in migrant communities points to the structural and linguistic barriers that may

Download English Version:

<https://daneshyari.com/en/article/8960784>

Download Persian Version:

<https://daneshyari.com/article/8960784>

[Daneshyari.com](https://daneshyari.com)