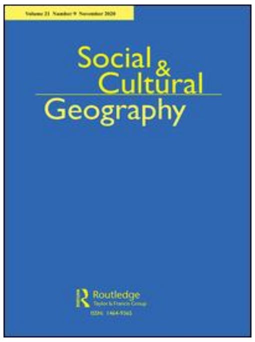

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The temporalities of supported decision-making by people with cognitive disability

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ABSTRACT

In many societies, people with cognitive disability have been presumed to lack reasoned decision-making capacity. Consequently, substituted decision-making laws and practices have traditionally authorised some people such as parents, guardians or medical professionals, to make decisions on their behalf. Several countries are now moving towards an alternative supported decision-making paradigm whereby people with different cognitive abilities are supported to make decisions that reflect as much as possible their 'will, preferences and rights'. In this paper we examine how geographical thinking about temporalities might illuminate some of the legal, ethical and practical complexities of supported decision-making. The paper draws on qualitative data from interviews with people with intellectual disabilities or acquired brain injury, and those who support them in making decisions. We examine how temporal scales and boundaries shape the determination of decision-making capacity; how decision-makers' 'will and preferences' are interpreted by supporters; and how the labour of support for decision-making is organised. We argue that further geographical engagement with supported decision-making can help significantly advance this important disability rights agenda.

Les temporalités de la prise de décision assistée par les personnes en situation de handicap cognitif

RÉSUMÉ

Dans beaucoup de sociétés, on considère que les personnes en situation de handicap cognitif n'ont pas la capacité de prendre des décisions rationnelles. Par conséquent, des lois et des pratiques pour substituer la prise de décision ont traditionnellement autorisé des tiers, tels qu'un parent, un gardien ou des professionnels de la santé à prendre des décisions en leur nom. Plusieurs pays s'orientent maintenant vers un modèle alternatif de prise de décision assistée par lequel des personnes avec des handicaps différents sont assistées avec des prises de décisions qui reflètent

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PALABRAS CLAVE
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le plus possible leurs « volontés, préférences et droits ». Dans cette communication, nous examinons la manière dont la pensée géographique concernant les temporalités pourrait illuminer certaines des complexités juridiques, morales et pratiques de la prise de décision assistée. Elle s'appuie sur des données qualitatives provenant d'entretiens avec des personnes en situation de handicap intellectuel ou de lésion cérébrale acquise, et celles qui les assistent à prendre des décisions. Nous étudions comment les échelles et les limites temporelles forment la détermination de la capacité pour la prise de décisions; comment « la volonté et les préférences » des personnes qui prennent les décisions sont interprétées par les personnes qui les soutiennent; et comment le travail du soutien pour la prise de décision est organisé. Nous soutenons qu'un engagement géographique plus poussé envers la prise de décision assistée peut considérablement promouvoir cette cause importante des droits des personnes handicapées.

Les temporalités de la prise de décision assistée par les personnes en situation de handicap cognitif

RESUMEN

En muchas sociedades, se ha supuesto que las personas con discapacidad cognitiva carecen de una capacidad de toma de decisiones razonada. En consecuencia, las leyes y prácticas de toma de decisiones sustituidas tradicionalmente han autorizado a algunas personas, como padres, tutores o profesionales médicos, a tomar decisiones en su nombre. Varios países se están moviendo ahora hacia un paradigma alternativo de toma de decisiones con apoyo mediante el cual las personas con diferentes capacidades cognitivas reciben apoyo para tomar decisiones que reflejen tanto como sea posible su 'voluntad, preferencias y derechos'. En este artículo examinamos cómo el pensamiento geográfico sobre las temporalidades puede iluminar algunas de las complejidades legales, éticas y prácticas de la toma de decisiones asistida. El documento se basa en datos cualitativos de entrevistas con personas con discapacidad intelectual o lesión cerebral adquirida, y con quienes las apoyan en la toma de decisiones. Examinamos cómo las escalas y los límites temporales dan forma a la determinación de la capacidad de toma de decisiones; cómo los partidarios interpretan la 'voluntad y preferencias' de los tomadores de decisiones; y cómo se organiza la labor de apoyo a la toma de decisiones. Argumentamos que una mayor participación geográfica con la toma de decisiones con apoyo puede ayudar a avanzar significativamente en esta importante agenda de derechos de las personas con discapacidad.

Introduction

Having a voice in decisions about matters that affect one's life is an important aspect of 'personhood' (Flynn & Arstein-Kerslake, 2014) and self-determination (Shogren et al., 2017). In many societies, people with cognitive disabilities have been, and continue to be, denied the right to make decisions. They are often denied opportunities to make major or minor decisions that affect their lives which 'tend to be characterised by a high degree of compliance with others' goals and agendas' (Macpherson et al., 2016, p. 385).

Premised on a perception that they lack capacity to make reasoned decisions that serve their own 'best interest', many have been subjected to substituted decision-making whereby other people and institutions – such as parents, guardians, or medical professionals – are authorised to make decisions on their behalf (Bigby et al., 2017). Substituted decision-making has been applied to both major life decisions (for instance, in relation to significant health procedures or housing transitions), as well as everyday decisions, such as financial expenditures, participation in services or daily routines, from the contents of breakfast to determination of bedtime. Similar substituted decision-making regimes and practices have also been applied to other populations and circumstances, such as people with psychosocial disability (Gooding, 2013), anorexia (Carney et al., 2005), or end-of-life care (Wareham et al., 2005).

In this paper we address the ethical, legal and practical conundrums of substituted decision-making affecting people with cognitive disability, and recent developments towards an alternative supported decision-making paradigm invigorated by the 2006 United Nations' Convention on the Rights of Persons with Disability (CRPD). Rather than making decisions for a person with cognitive disability, supported decision-making involves supporting that person to make decisions that reflect as much as possible their 'will, preferences and rights'. Countries such as Ireland, Canada and Sweden have implemented significant legislative reforms in this direction. Other countries, including Australia, have implemented more partial supported decision-making reforms as we elaborate in the following section. From a disability rights perspective, the shift from the paternalism of substituted decision-making is a welcome development. Yet, critical investigation of what 'will, preferences and rights' mean, and how they might be ascertained in the case of people with significant cognitive disabilities defies any straightforward interpretation and has seldom been empirically explored (Carney et al., 2019).

The first objective of the paper is to examine how geographical thinking about spatial and temporal relations might illuminate hidden or misconceived aspects of supported decision-making. As pointed out by Milligan and Wiles (2010), spatial relations such as proximity or distance influence whether and how we care *about, for* and *with* others. In this paper we examine similar questions on how temporal and spatial relations influence substituted and supported decision-making. We argue that temporal scales and boundaries are central to the way will and preferences are interpreted in theory and in practice. Further, we demonstrate how the temporal organisation of care labour shapes power relations in decision-making processes.

Our second objective is to consider how debates on support for decision-making might inform geographical theorisation of time-space. The paper offers insights on the concepts of temporal scales and boundaries as aspects of the so-called 'structural features' of time and temporality (Adam, 2000; Schwanen & Kwan, 2012) and demonstrates the significance of these in the construction of identities, self-determination and the exercise of power in decision-making processes.

A brief comment on terminology: we distinguish in the paper between 'supported decision-making' as the legal and policy structures underpinning support for decision-making, and 'support *for* decision-making' as a set of practices performed by supporters to assist a person in a decision-making process. In using the term 'people with cognitive disability', we refer here to both people with intellectual disability (as a lifelong condition from birth), and people who experienced cognitive impairment as a result of acquired brain injury (ABI). In both cases, cognitive disability is associated with reduced ability to understand or communicate new or complex information, and to learn and apply new skills (Australian Bureau of Statistics (ABS), 2012).

The paper is structured as follows. First, we discuss the shift from substituted to supported decision-making in Australia, drawing attention to its institutional, legislative and socio-cultural dimensions. Second, we describe our study methods. Third, we present empirical analysis of the role of temporal scale and boundaries in relation to three aspects of support for decision-making: constructions of decision-making capacity; constructions of 'will' and 'preferences'; and the labour of support for decision-making. Finally, we discuss how geography and the scholarship on supported decision-making might inform one another.

From substituted to supported decision-making

As context for our study, in this section we present an overview of the institutional, legislative and socio-cultural dimensions of the transition from a substituted to a supported decision-making regime in Australia and internationally. Specifically, we draw attention to direct and indirect engagement of geographical scholarship with these themes.

The institutional front

Historically, the regimented daily routine of institutions, and the strict hierarchal relations between staff and residents (Goffman, 1961), have denied opportunities for decision-making by residents with cognitive and psychosocial disabilities (Then, 2013). Even in those countries where several decades of deinstitutionalisation saw the closure of state-run institutions, many people with cognitive disability continue to live in institutional settings such as prisons, nursing homes or psychiatric hospitals (Wiesel & Bigby, 2015), where decisions affecting their lives are made by staff. Further, while the majority of people with cognitive disability are no longer, or never were, confined to a single 'total institution' (Goffman, 1961) encompassing all spheres of life, geographers have pointed out that many continue to attend primarily 'specialist' disability places and services – such as group homes, special education schools, or day centres – where certain institutional practices are maintained (Hollomotz & Roulstone, 2014) and decision-making rights and opportunities continue to be compromised.

Support practices of paid disability support staff often restrict decision-making autonomy for people with cognitive disability, partly due to inadequate training and supervision (Antaki et al., 2009). Funding structures also impact on decision-making autonomy. A shift away from block-funded services to direct payments in several countries, including Australia's National Disability Insurance Scheme (NDIS), was justified as a means to empower people with disability by granting them the power to make decisions about their preferred support providers. The NDIS will see the vast majority of block funding for specialist disability services replaced by individualised funding as a mechanism to enhance 'choice and control' for recipients; an estimated 60 per cent of whom will have a cognitive disability (Bigby, 2016). The move to individualised funding and market driven models of human service delivery, as exemplified in the NDIS, means that people with cognitive disability are confronted with more decision-making situations, and an increase in the range and complexity of decisions they are expected to make. At the same time, under an individualised funding model, funding available for training of disability support workers is reduced, creating a more precarious workforce (Wiesel et al., 2019) that is prone to poor quality in support for decision-making.

Although to date Australia has not implemented substantial supported decision-making legislation – as discussed in the following subsection – the NDIS is underpinned by legislation under which it is required to assume, so far as is reasonable in the circumstances, that its participants have capacity to determine their own best interests and make decisions that affect their own lives (Bigby et al., 2017).

The legislative front

Substituted decision-making legislation – such as guardianship laws – have existed since at least Roman times, and gained traction with the rise of the medical profession, and a wide societal understanding of disability as a pathological medical condition, i.e. the 'medical model' of disability (Then, 2013).

In a substituted decision-making regime, a person's legal status is determined by their presumed ability to make decisions. People with significant cognitive disability who are deemed lacking legal capacity may be subject to formal arrangements of substituted decision-making, for example, through the appointment of guardians and administrators, vested with power to make decisions on their behalf. In Australia, guardianship or administrative orders since the 1980s have been framed as 'last resort' mechanisms, and substituted decision-makers are required by law to take account of both the preferences and 'best interests' of the person (ALRC, 2014). Among critics of substituted decision-making, a matter of debate is whether the appointment of a person with formal powers to make decisions on behalf of another person is an injustice in itself; or, whether what matters are the practices of substitute decision-makers, and whether they privilege 'best interest' over the preferences of the person affected by these decisions (ALRC, 2014, p. 88).

The 2006 United Nations Convention on the Rights of Persons with Disability (CRPD), ratified by Australia in 2008, enshrines the right of people with disabilities to make decisions affecting their lives on an equal basis with other citizens (Kohn et al., 2013). This involves a shift from the presumption of legal incapacity on the basis of disability, to an emphasis on the nature of support that people with different abilities need to exercise decision-making. In some countries – such as Ireland, Canada and Sweden – supported decision-making is now afforded legal status (Gordon, 2000; Then et al., 2018; Tideman, 2016), although there is little or no evidence of its impact on practice (Bigby et al., 2017).

The Australian Law Reform Commission (ALRC, 2014) and Commissions in several Australian jurisdictions such as Victoria, New South Wales, Tasmania and the Australian Capital Territory, have all recommended reform to guardianship legislation, including new laws that afford legal status to decision-making supporters (Then et al., 2018). These recommendations are underpinned by recognition of four principles: people with cognitive disabilities' equal right to make decisions; the need to provide adequate support to enable decision-making by people with cognitive disability; decisions are to be directed by individual's 'will, preferences and rights'; and legal frameworks are necessary to protect against abuse and undue influence. To date, however, with the exception of limited reforms in Victoria, there has been no legal reform that affords supported decision-making a legal status, as has occurred in Canada or Sweden. Indeed, the Australian Government has reiterated that in its interpretation, the CRPD does not require the abolition of all substituted decision-making regimes and mechanisms (ALRC, 2014, p. 55).

Despite geographers' interest in global inequalities in the realisation of disability rights, including the right to full and equal participation in society (Chouinard, 2018), the paradigm shift from substituted to supported decision-making has not yet been addressed in legal geographies.

The socio-cultural front

Regardless of legislation, a great deal of decision-making occurs informally, where decision-making support or substitution is often provided by family or friends. Further, even in formal decision-making processes, decision-making supporters' practices are mediated by cultural norms. Cultural perceptions about people with cognitive disability play a key role in how supporters assess their ability to make decisions and what support they might need. Other personal factors – such as age, sex, education, race, ethnicity, and language of the support providers or recipients – also shape the nature of support for decision-making (Shogren et al., 2017).

Values and attitudes in relation to personal autonomy, collective responsibility and risk are thus pertinent to how support for decision-making is delivered in different societies (Carney, 2012), by different institutions (Gooding, 2013) and different individuals. For instance, perceptions of risk – from risk-aversion to recognition of the dignity of risk – significantly influence the practice of support for decision-making (Gooding, 2013). Likewise, while personal autonomy is privileged in many western societies, in other cultures greater emphasis is placed on collective interests in decision-making. For instance, in New Zealand the introduction of legislation pertaining to Advance Directives – whereby individuals may convey their wishes about accepting or refusing future end-of-life medical treatment – was met with strong resistance from Maori communities, where medical decisions are considered to be collective as opposed to individual decisions (Wareham et al., 2005). Similar cultural tensions apply in relation to decision-making by people with cognitive disability.

In geographical scholarship there has been a long engagement with the socio-cultural dimensions of decision-making by people with cognitive disability. Geographical analysis has focused more broadly on issues surrounding the self-determination of people with cognitive disability, through analyses of their agency in 'self-building' spaces (Power & Bartlett, 2018); participation in art (Macpherson et al., 2016), peer-support and self-advocacy (Power et al., 2016); the negotiation of everyday spaces (Hall, 2005; Holt, 2007; Power & Bartlett, 2018; Wiesel & Bigby, 2016; Wilton et al., 2018); and the co-production of knowledge (Holt et al., 2019; Murray, 2019). Despite geographers' ongoing interest in questions surrounding the self-determination of people with cognitive disability, explicit and direct links to supported decision-making have rarely, if ever, been drawn.

Method

The qualitative data presented below is derived from a study that examined decision-making by people with cognitive disability, and their supporters' practices before and after participation in a training workshop based on an evidence-based innovative practice framework. The project was led by an interdisciplinary team of researchers from social work, clinical neuropsychology, law, and geography.

Participants in the research were dyads consisting of a decision-maker with cognitive disability and their decision supporter. Decision-makers were all aged 18 years or over who self-identified as having either an intellectual disability (mild to moderate) or an acquired brain injury and were able to participate in an interview either independently or with support. Supporters were people who knew the decision-maker well and who worked on decisions with, and sometimes for, them. Supporters were 18 years or over and included parents, other family, spouses, or paid workers such as support workers. All participants lived in the Australian states of Victoria, New South Wales, or Queensland. Members of dyads were interviewed separately before, and in some cases also after, the training workshop for supporters.

The interview was structured to understand the nuance of supporters' practices, and decision-makers' experiences. Both decision-makers and supporters were asked about their relationship, about decisions that affected the person with cognitive disability and the processes of support involved in reaching final decisions. Participants spoke about a wide range of decisions, from choosing what to wear to where to live.

For this article, we drew on data from the first round of interviews that took place before training, with a total of 77 dyads (including 55 with a person with intellectual disability, and 22 with a person with ABI). Using a geographic lens, initial analysis of the interview transcripts identified three sub themes related to temporality: how perceived need for support in decision-making changes over time; how decision-makers' will and preferences change over time; and how the time-intensive labour of support for decision-making is organized and managed. In our analysis below, we map these three sub-themes onto wider discussions in the literature on support for decision-making, offering a unique temporal perspective into questions about legal capacity, 'will and preferences', and support for decision-making as labour.

To allow more in-depth engagement, in the analysis presented below we have focused specifically on six dyads whose stories offered particularly rich insight on the three themes outlined above. They also represented a mix of decision-makers with both intellectual disability and ABI, and formal and informal supporters. Participants in this sub-cohort were interviewed separately from their dyad partners. These six dyads included:

Taylor and Peter: Peter was a key support worker in a residential facility where Taylor had lived several years. Taylor was in her mid-30s at the time of participation, and experienced a cognitive disability due to a brain injury acquired in her youth. During the interviews Taylor and Peter spoke about decisions concerning her relationships with men.

Lee and Karen: Lee was in his early 30s when he participated with his then girlfriend Karen – also in her early 30s. Lee had sustained a brain injury some 15 years before. At the time of the first interview, Karen and Lee had decided to stop living together in Lee's dwelling which had on-site support staff.

Nicole and Frank were another couple who participated. Frank experienced several injuries over the previous 10 years resulting in a brain injury. Nicole and Frank had two children and they lived together at the time of the first interview. Both spoke about their relationship as a couple and as a care giver and recipient.

Alara and Eda: Alara was in her early 30s and she worked in supported employment as well as volunteering at an animal shelter. Alara had an intellectual disability, and her mother Eda was her decision supporter. Alara was interested in buying a house and living independently and this was a decision that they both discussed in their first interview.

Zara and Carol: Zara was in her mid-30s at the time of the first interview. She had an intellectual disability and was supported by her mother Carol. Both Carol and Zara spoke about a plan for Zara to move an hour away where she could attend a college for people with cognitive disability.

Aria and Freya: Aria, a woman with intellectual disability in her early 20s, living with her parents, and supported by a paid worker, Freya, whom she had known since she was in primary school. Freya was in her late 30s at the time of the interview and employed to work with Aria on her goals, including her expressed desire to move overseas.

The temporalities of support for decision-making

Time scales, frames and boundaries of decision-making capacity

Time scales, frames and boundaries are central to the way decision-making capacity is determined in formal frameworks, such as ‘legal capacity’ legislation, as well as informal practice. For Adam (2000), time scales are general units through which time is measured (as in a day, a year, an epoch), while time frames pertain to specific times bounded by a beginning and end (as in today, next year, the Holocene) (Schwanen & Kwan, 2012). Temporal ‘boundaries’ can be understood as discontinuities in the flow of time. As Munn (1992, p. 112) observed, the flow of time can be experienced as a causal incremental progression on a continuum where one moment leads to another. Alternatively, time can be broken into episodes experienced as unpredictable discontinuities rather than logical progression.

Whether decision-making capacity is framed as a permanent, episodic or contingent condition, influences how and by whom it is determined. The view that people with cognitive disability are *never* capable of making decisions, presents decision-making capacity as a permanent condition (Carney et al., 2019). When decision-making capacity is framed as permanent, the power to determine it rests primarily with health professionals, in line with a predominantly medical model of disability.

Alternatively, decision-making capacity is sometimes framed as a temporary condition, either as a life-course phase, or as an episodic mental condition that may come and go. Childhood, for example, is often understood as a life-course phase in which capacity for reasoned decision-making is not yet fully developed. In contrast, some older people are deemed by professionals to have once had, and to have later lost, decision-making capacity (Carney, 2012). A person may also be considered as generally capable of making decisions, yet incapable for a time-limited period such as a manic episode. On the legislative front, such a more flexible view of decision-making capacity as temporary rather than permanent is reflected in practices such as reviewable guardianship orders in place of indefinite ones (Carney, 2012). Even so, medical professionals often still retain the power to define the temporal boundaries of episodes, as a clinical diagnosis of decision-making capacity.

The decision-making capacity of people with intellectual disability is understood by some as a permanent condition that has affected them all their lives, whereas for people with ABI decision-making capacity is understood to have radically changed after the brain injury. This distinction influences how people are supported to make decisions, and how their 'will' and 'preferences' are interpreted, as elaborated in the following section.

However, consistent with the current legal view, many participants in our study understood decision-making capacity as contingent to the specific context of each decision. Assessing decision-making capacity thus required personal familiarity with the decision-maker, rather than a clinical understanding of cognitive impairments. For instance, Peter described the contextual factors impacting on Taylor's ability to make decisions, and the circumstances in which she is more vulnerable to manipulation:

> This is where a lot of her decision making problems can arise, when that type of pressure is put on her out and about. On the telephone she can say no. As soon as you get her [out of] her home environment and start chipping away at her it just erodes that decision-making capacity and before you know it she's saying yes to stuff she doesn't want to do and that's the problem … It's context related, it is context related but really only with those sexual relationships, she'll struggle with those (Peter)

Rather than a medical assessment of Taylor's cognitive condition, Peter's emphasis is on the spatial and temporal context in which decisions are made, and the nature of the decision itself. In spatial terms, Peter frames Taylor's decision-making capacity as contingent to the 'environment' in which she makes decisions, and whether it is an environment in which she is 'protected' by supporters, or one where she is more vulnerable to exploitation. In temporal terms, rather than a fixed condition, Peter frames Taylor's ability to make decisions as a capacity that can be eroded by people who are 'chipping away at her'.

Peter's quote also illustrates the way support for decision-making is culturally mediated. Peter claims Taylor's decision-making capacity is particularly compromised in the context of sexual relationships. His attitude reflects the contentiousness surrounding sexuality by people with cognitive disabilities and its framing as a 'risk' or a 'right'. Over the last decades, there has been growing recognition of people with cognitive disabilities' right to experience and express some aspects of their sexuality. At the same time, people with cognitive, and particularly intellectual disabilities, are more likely than others to experience sexual abuse, and often lack 'sufficient knowledge about sexual matters to protect themselves against exploitation' (Cuskelly & Bryde, 2004). Consequently, support workers' attitudes towards sexuality are often framed in terms of 'risk', and an emphasis on protection from abuse, as evident in Peter's quote above. Coupled with the stereotyping of people with intellectual disabilities as sexually deviant or asexual, and continued concerns about parenting by people with intellectual disabilities, such attitudes often lead to discouragement of any forms of sexual expression (Cuskelly & Bryde, 2004; McConkey & Ryan, 2001).

The framing of Taylor's decision-making capacity as spatially, temporally and decision-specific contingent challenges the medical model of decision-making capacity, which underpins substituted decision-making. Yet, such a framing does not necessarily guarantee best practice in support for decision making, which can be undermined by culturally-mediated discourses and practices such as the 'risk' paradigm applied in relation to sexuality.

Time scales, frames and boundaries of 'will and preferences'

Time scales and frames are central to the distinction between 'will' and 'preferences' as understood in some legal, institutional and practice discourses. In the CRPD the terms will and preferences are always paired together, neither distinguished nor defined, and these terms have no clear definition in most legal systems (Szmukler, 2019). A similar observation can be applied to the ALRC report. Regardless of their formal status on the legislative front, we argue that on the socio-cultural front intuitive interpretations of will and preferences – even if not explicitly named as such – impact on support for decision-making practice.

Drawing on the work of other philosophers and legal scholars, Szmukler argues for an interpretation of preferences as momentary inclinations, and will as a more stable set of higher-order personal values:

> The 'will', on this view, can be seen as founded on a person's deeply held, reasonably stable and reasonably coherent personal values. In this sense, it is not the same as a desire, inclination, or a currently held 'preference', even a strongly expressed one. (Szmukler, 2019, p. 93)

This distinction – indeed hierarchy – between will and preferences rests on both normative and temporal grounds. In a normative sense, will – as higher-order values – is privileged over preferences as either juvenile, superficial desires; or, as simply derivatives of will. In a temporal sense, preferences are contingent and fleeting while will, although not static, is 'reasonably stable', operating on a long-term scale over the life-course.

For the most part, Szmukler argues will and preferences 'run together' (p. 93) and appear compatible with one another. Indeed, for this reason, Szmukler argues that one's will can be induced through observation of past decisions and expressed preferences; and likewise, a person's preference at a particular moment – even if they struggle to articulate it – might be deduced by those who know their long-held 'will'. Indeed, several supporters interviewed in our study acknowledged that they rely heavily on past experiences with the person they support to deduce their preferences on a current decision.

Yet, in certain circumstances contradictions may appear between a person's presumed will and their stated preference. In such events, under the hierarchy constructed by Szmukler (2019), will trumps preferences. For instance, a person experiencing a manic episode might wish to donate all their belongings to someone else and, following recovery, would desperately regret that decision and its irreversible impact on themselves and their family (Galderisi, 2019).

Therefore, whether a person's stated wish is understood by their supporters as a 'preference' or as an expression of 'will' influences how they are supported. Aria, for example, described a case where supporters ignored her wish to move from Australia to the United States to become a performer:

> Decisions I really want and they're not helping me with is for someone that wants to live overseas how would I do that? As far as I'm concerned I'd much rather live in the US than here because it's better and Donald Trump and I don't want the Australian government. I just feel that I just can't live in Melbourne for a few reasons like I'm not liking the travel system here. Every time I get in trouble for something with the police and the inspectors around makes it really hard … . I've been there for holiday to LA and San Francisco and I can really really picture myself living in the US. I can picture myself being on a stage with big singers. … . not very happy how Freya [supporter] is support for my two dream goals like I feel that this is never going to come true … I'm just afraid they're going to stop me. (Aria)

One way to interpret Aria's story is to classify her aspiration to move to the United States and start a show business career as her deeply-held will (or 'dream goals' in her terms). Her supporters' refusal to assist her in fulfilling this wish might be interpreted as their privileging of what they perceive as Aria's objective best interest (keeping Aria close to her existing support network) over her stated will. An alternative interpretation would classify Aria's American Dream as merely a 'preference'. Her supposedly 'true will', then, is apparent not in her wish to move to the United States, but in the reasons for it: a desire for a life of creativity, and for freedom and security in the public realm. From this perspective, Freya's objection to Aria's expressed preference is necessary to support Aria in fulfilling her will for a creative, free and safe life, whether in Melbourne or in San Francisco. This example demonstrates that the distinction between substituted and supported decision-making can be a fine line at times and depends to a large extent on supporters' interpretation of a person's stated wish as a fleeting preference or a long-held will.

Szmukler's (2019) notion that will can be ascertained through observation of past preferences raises unique dilemmas for people with ABI: is a person's true will evident in their decisions before their ABI, apparently free of any distortions associated with the injury? Or, alternatively, does the injury represent such a radical discontinuity in one's identity, that their pre-injury preferences tell little about their post-injury will? Indeed, many people with ABI experience an ongoing process of reconstruction of self-identity marked by a temporal framing of 'before' and 'after' the injury (Douglas et al., 2015). Yet, while the injury represents a temporal boundary in some aspects of self-identity, it is also part of a continuum in other respects. It is useful to distinguish here between personal attributes and personal goals, both aspects of self-identity. After an injury, many people with ABI continue to self-identify with personal attributes or characteristics from before the injury, alongside some newly recognized attributes shaped by experiences after the injury. Yet, the injury and its consequences often mark a significant temporal boundary – or discontinuity – in terms of personal goals. After their injury, striving to live well with their impairment, many people reassess their personal goals which continue to change over time (Douglas, 2013; Douglas et al., 2015a; Knox et al., 2017).

Such questions about temporal boundaries, and continuity of will after a brain injury, were a key theme in Lee's interview. Lee described the accident in which he acquired a brain injury as a significant temporal boundary in his biography, but like many others with ABI (Douglas, 2013), also stressed his refusal to identify himself only in reference to that event:

> I remember November 3rd [date of accident] better than I remember my own birthday, hilarious. What I really wanted to cool this back down to is that is very much who I associate

> with but I am not my head injury, that is not who I am, but it seems to have affected my life that much (Lee)

Lee emphasised how certain personal attributes, such as creativity, have endured after the injury. Yet, some of his personal goals have changed in both positive and negative ways, that should be acknowledged when considering how past preferences might reflect on his current will:

> The difficulty of ABI in a sense is it doesn't only take away from you some abilities that you might've had, it certainly does but I guess it also gives you some insights that some people will never get I think, but it also is a setback literally in your development . . . I've kind of lost my identity. It's been lost in what I've categorised myself as, or allowed myself to be categorised as which is an ABI patient . . . But with all that in mind I don't forget the positive – I guess I started off by saying a creative person. I love artwork . . . I find very fulfilling I guess. So I'm a nice guy, I don't know how to put this, but I have goals and I also have deficits that I'm aware of, and one of the deficits is in fact amnesia. (Lee)

Temporal distance presents additional risks in interpreting will based on supporters' memories of past preferences. Memory is not always reliable since it 'involves both deliberately and unconsciously selective interpretations of the past that may be evoked differentially, under different circumstances' (Bowlby, 2012: 2106). For example, Carol acknowledged occasionally making decisions *for* her daughter Zara based on her knowledge of Zara's preferences in past decisions. But Carol also explained that it is difficult to 'make a blanket' (or to generalise one's 'will') based on past decisions Zara had made in different contexts:

> Do I choose for her? Sometimes. Because you tend to think of a specific decision, and so it's quite difficult to make a blanket because I think it can vary depending on the decision. (Carol)

The privileging of will over preferences could potentially be manipulated and misused by supporters, for instance, by framing a preference as will or vice-versa, as illustrated above. In most cases of everyday decisions, the privileging of long held 'values' over momentary 'inclinations' is also problematic since it reflects a normative view of personhood as a strict plan that must be followed through consistently, and where experimentation, change and self-exploration are devalued and discouraged. Yet, in more extreme cases where expressed preferences are not only contradictory to a person's presumed will, but indeed may cause it irrecoverable damage (as in Galderisi, 2019 example of a man donating all his belongings during a manic episode), the privileging of will (even if inferred by others) over preferences (even if explicitly expressed by the person) may be justified even within a supported decision-making paradigm. Likewise, when neither will nor preferences can be ascertained – say in the case of an unknown stranger who is unable to communicate their wishes – substituted decision-making must be made based on 'rights' as the backstop (Carney et al., 2019).

Time boundaries and the labour of support for decision-making

In feminist literature, caring for a person is often described as a form of labour. Framing care as labour is an ethical position against economies where the emotional and physical effort, and the time invested – primarily by women – in giving care is devalued and poorly rewarded (Tronto, 2001).

The care labour of support for decision-making is temporally fluid, in the sense that it is rarely restricted to a well-bounded timeframe dedicated to supporting a decision, rather it is typically more dispersed and spills into other temporalities of daily routines. Some participants in our study described the process of providing support for decision-making as involving a mix of both planned ('formal') sessions and incidental ('in passing') moments:

> Yeah, so any time we sit down she likes that [talking through a decision], though if you go into too much detail the eyes start closing. We often mentioned it in passing. Yeah, probably mainly in passing, kind of things that she might need to think about come up … Maybe a couple of more formal sessions … Because otherwise she's just overwhelmed with information (Carol).

Decisions vary in the timeframe in which they must be made. When decisions are not urgent, more time can be dedicated to a careful process of support for decision-making. In some cases, such processes can extend over months or years, as in the case of Alara's decision to move out to live independently. Rather than a decision that needs to be made in the short term, Eda is focused on assisting her daughter Alara to develop the skills necessary to choose a house, in a slower long-term process:

> So I thought about buying [a house], like, I have looked around before but I thought, because I'm 28, I'd rather like, instead of – I'd like to be independent on my own. So she [mum] knows that and I know that (Alara)

> So we've even gone to housing [inspections] and had a look … But something that is big like this, I just feel very hesitant in making that final decision. But I would, of course, have to speak to her about it. It's not my decision. At the end of the day, she's going to live in it. But giving her the right advice financially and all of that … I always say to her, have a look at the houses around you. Are they well-kept? Or are they overgrown and broken windows and that. Because that sort of, like, tells you what sort of an area you're moving into. (Eda)

Other decisions need to be made within a brief timeframe, at times on the 'spur of the moment', as expressed by one supporter interviewed. The quality of support for decision-making processes can be compromised when restricted by time, and some supporters acknowledged making decisions *for* a person under such pressure. At the same time, an overly drawn-out decision-making process can also potentially delay or prevent a decision, and as such can potentially be no less restrictive.

The quality of support for decision-making improves when supporters have known the decision-maker for a long time and are able to interpret their will and preferences with more confidence (Douglas & Bigby, 2020). At the same time, close long-term relationships – such as those between relatives – enhance the emotional burden associated with support for decision making. Rather than neutral observers, family members are likely to be personally affected by their relative's decision, or to hold strong wishes and desires for that person, and as such can be deeply emotionally invested in the process of support for decision-making.

Getting to know a person – spending time in each other's presence, conversing or doing things together – may not always be experienced as labour. Yet, maintaining the continuity of a relationship over time, often in the face of significant stress and difficulties, can be understood as substantial emotional labour invested both directly and indirectly in the practice of support for decision-making. Examples in our study of the emotional labour experienced by both decision-makers and their supporters were: managing intense emotions when negotiating conflicting views on a decision (Eda and Alara); maintaining an ongoing care relationship in the face of the breakdown of an intimate couple relationship (Nicole and Frank); and managing personal boundaries in the context of formal support arrangements (Peter and Taylor).

> Sometimes she hates me. If I don't agree with what she's doing or if I'm not doing – it's more like if I don't do what she wants right there and then, right then and now. (Eda)

> Currently our relationship is very strained. It's close to non-existent other than my functionality as a carer. (Nicole)

> Peter's like a second father but I don't want a second father (Taylor)

For paid support workers, in addition to the emotional challenges, maintaining continuity of care becomes difficult in the context of precarious labour. The shift to individualised funding under the NDIS was promoted as having potential to deliver greater 'choice and control' in allowing participants to move their funding from one service to another. However, this shift has also led to more precarious labour for disability support staff (Wiesel et al., 2019), undermining their capacity to get to know service users well, which is an essential condition for successful support for decision-making.

Participants explained how intense emotions associated with giving support for decision-making impact other aspects of their everyday lives. For Nicole, for example, the labour of supporting Frank in making decisions is 'just constant', because

> … he's constantly asking questions, or just talking to me. I call it talking at me, for the sake of just verbalising out loud because it's easier than try and do it in his head, and maybe he gets some confidence from that, knowing that someone's listening in case that I can provide some input. (Nicole)

Nicole describes the labour involved in supporting Frank's decisions as physically and emotionally draining. It occurs simultaneously to her work as an owner of a small business run from home, and thus affects both her personal and professional life:

> I run a small business from home as well. That's my office. And it's right in the middle of the living area … I'm just getting so drained, physically and emotionally, that I just feel like I'm shutting down, and I'm struggling to make decisions now, because I have to switch off, emotionally, so that I don't just fall apart (Nicole)

In Nicole's narrative, the temporal and spatial dimensions of the labour of supporting Frank's decision-making are inextricably linked. The blurring of 'home' and 'work' spaces reinforces the blurring of 'formal' and 'in passing' temporalities of her care labour, exacerbating her sense of falling apart. In contrast, from Frank's perspective, Nicole's support significantly reduced the intense cognitive and emotional labour he typically experiences when making both large and small decisions on his own:

INTERVIEWER: So, what was it like, that process of having that chat with Nicole? Did you find that a good thing; helpful?

FRANK: Yeah, it was good, because it helped resolve a question really.

Several supporters explained that they determine the amount and nature of support they give based on the level of risk involved, which they assessed in temporal terms. Decisions perceived as ‘small’ (shorter-term effects), were considered less important and risky, and some supporters left decision-makers to decide on these ‘independently’ with little or no support, or alternatively opted for the quick fix of substituted decision-making, as a strategy of rationalising labour:

> If I don’t think that the decision is a high enough priority that there’s going to be no adverse effects from it. If it’s just something really minor that he’s obsessing about, for whatever reason, and my input’s inconsequential or not being received or any of this sort of stuff, I will just go, “Yes well whatever” and leave him to it . . . At the end of the day they’re not usually life or death decisions, so you can do your best and be happy and confident that you’ve done the right thing. And if not, it’s not the end of the world. (Nicole)

While the perceived risk associated with any one ‘small’ decision is minimal, the cumulative effect of countless decisions made with little or poor support, can be no less significant in a person’s life than supposedly few ‘big’ decisions. At times, this approach reduced decision-makers’ confidence in the support they received:

Interviewer: [On the scale of 1 to 10] thinking about the confidence you have in the support that you get from Nicole around decisions?

Frank: Probably a six . . . She hasn’t always got the time to put in.

Discussion

In this paper we have demonstrated that considerations relating to time and temporalities must be accounted for as critical components of supported decision-making legislative, policy and practice frameworks. Time scales and boundaries are central to the way decision-making capacity is assessed, how supporters interpret will and preferences, and how they assess the importance of decisions and prioritise their support labour accordingly. Self-determination is more likely to be compromised when a person is considered lacking decision-making capacity for a defined time period, without consideration of the context of each decision. Likewise, self-determination can be compromised when long-term will – as interpreted by supporters – is privileged over momentary preferences expressed by decision-makers. Other risks arise when decisions with perceived short-term impacts are poorly supported as a strategy of rationalising care labour, ignoring their cumulative implications, or when insufficient time is allocated to the process of decision-making.

Acknowledging support for decision-making as labour that is not only time-intensive, but also temporally fluid and never fully contained within bounded sessions, is also a critical consideration in devising programs to assist both paid and informal supporters. A key issue here is the need to maintain continuity of care over time, in the context of individualised funding and growing precarity for paid supporters, and intensive emotional labour for unpaid supporters as well as decision-makers themselves. As observed by Macpherson et al. (2016: 383), careful listening to artists with a learning disability requires a ‘slow temporality’, spending significant amounts of time together, learning a person’s ways of expression and building trust over a long timeframe, sometimes many years, while also being attuned to their present expressions. A similar slow temporality is often necessary for quality support for decision-making, although more urgent decisions may not allow this.

This analysis of support for decision-making for people with cognitive disability offers rich insight for wider geographical debates on time and temporalities. The paper contributes to the theorising of the structural features of time (Adam, 2000), and specifically the concepts of time scales and boundaries. The analysis shows how temporal constructions can be used as potent instruments of power, in some cases by legitimising substituted decision-making, in other cases by challenging it. Key examples include the privileging of certain time scales ('will', decisions with long-term effects) over others ('preferences', decisions with short-term effects), and the interpretation of events (such as a brain injury) as temporal boundaries, continuities, or both at once.

In conclusion, our paper contributes a new perspective to geographers' ongoing interest in questions surrounding the self-determination of people with disability. Complementing geographers' interest in people with cognitive disabilities' negotiation of everyday spaces as a key feature of their self-determination (Hall, 2005; Holt, 2007; Power & Bartlett, 2018; Wiesel & Bigby, 2016; Wilton et al., 2018), our paper highlights the significant but often overlooked temporalities of self-determination. Our analysis points to the need for careful geographical engagement with the complexity of decision-making by people with cognitive disability, acknowledging the elusive lines that often separate 'support' from 'substitution' of decision-making. Geographical thinking about time and space has much to contribute to, and learn from, analyses of supported decision-making by people with cognitive disability, as well as other people once deemed inherently incapable of making decisions. Specifically, geographers can contribute to understanding the interconnections between legal, institutional and socio-cultural factors impacting on support for decision-making, since they are all entangled spatially and temporally.

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