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Understanding the autonomy of adults with impaired capacity through dialogue

Introduction

Anna Smajdor invites welcome interrogation of the distance between our philosophical justifications of how we engage people in decisions about healthcare or research, and the ways we do so.¹ She notes the implicit elision made between autonomy and informed consent, and argues the latter alone cannot secure the former, proposing a more flexible approach.

As researchers working with people with dementia (PwD), we share Smajdor's reservations. We argue that an autonomy *worthy of respect* requires not just decision-making *capacity*, but also *authenticity*; the ability to determine for oneself what is good for oneself.² Furthermore, our relationships support or undermine both capacity and authenticity, and autonomous expression manifests throughout evolving relationships. This invites us to view respect differently – as an ongoing conversation with another person, capable of holding values that may move us. In Smajdor's terminology, it requires that we recognise them. We describe how we operationalise this in our research.

Autonomy worthy of respect

Three broad arguments usually support respect for autonomy.² One – owed to JS Mill – holds that permitting individuals free choice promotes utility of all, by helping them fulfil ideas of the good, demonstrating 'experiments in living'. Another draws from Kant's categorical imperative; its Formula of Humanity holds that the capacity to determine our own values gives us reason to act, and we ought therefore to treat others' values with the respect we show our own. Lastly, many simply assume 'liberal neutrality' - an intrinsic value in people being permitted to pursue the good in their own way.

Each of these arguments entails that respecting autonomy involves accepting others' decisions when able to make them; this aspect is (as Smajdor argues, imperfectly) captured in capacity law. However, they also require that these decisions are made on the basis of what is most important to the person. The autonomy literature is littered with capacious decisions that nonetheless fail to capture the person's values, whether through adaptive preference (like Aesop's fox who, unable to reach the grapes, convinces himself they are sour and thus does not wish them anyway), oppressive socialisation (internalisation of oppressive beliefs from immersion in a social context in which they are normative), or simple material constraint.²

What is lacking in these examples is not decision-making capacity, but rather the *authenticity* of the underpinning values. Our ability to make choices for ourselves, and for those choices to reflect what is most important to us, is bound to our social position – environment and community shape our decisions in ways that may support or constrain living autonomously.

Authenticity, capacity, and shared decision-making by and for PwD

As Smajdor argues, focussing solely on capacity captures the least interesting part of what is valuable about autonomy: “when we exclude [adults with impaired capacity] from research, we are taking their incapacity to be their defining feature.”¹

With appropriate support, PwD can communicate some of what matters most to them. Through building the necessary relationships, we can maintain some level of dialogue even through severe communication impairments. Qualitative research involving PwD highlights that they emphasise the importance of including supportive carers in their decision-making processes, and can identify the relationships they find most supportive. Certain decision-making procedures and relationship dynamics can leave PwD feeling unable to articulate their values; carers can misidentify preferences, or exclude PwD from decision-making.³

PwD value their inclusion. This resists the false dichotomy of either acquiescence to, or overriding choice:

“[My wife] still asks for my advice and I appreciate that...she’s considerate in the sense of always seeking my point of view regardless of whether she’s able to act on that. My point of view might be ... not much help in some circumstances, but she always asks for it.”⁴

In this quotation, ‘Jerome’ (a PwD) demonstrates the value of being taken seriously as someone with a distinct point of view – even as he recognises that point of view may not always be sufficient to guide appropriate action, or might need help to be articulated. He reflects what Smajdor calls ‘recognition’, acknowledging that another person has values that motivate them, sufficient to consider them potential motivation for us too. Such recognition does not prohibit challenging a person; but it requires taking their point of view seriously.

This invites us to change our understanding of ‘respect’ in respect for autonomy. We model our understanding of respect as a conversation. In respectful conversation, we can disagree with our interlocutor, but we attempt to construct a ‘shared space of reasons’ that all participants to the conversation agree constitute motivation to act.² We have to take their point of view seriously, accepting it could alter our own.

Respect in longitudinal research involving PwD

We are engaged in a longitudinal study of decision-making by and for PwD; we need to understand how to respect their autonomy. We aim to recruit dyads of PwD and carers from first diagnosis in the cognitive clinic, studying how decisions are made between PwD, carer, and health worker as their condition progresses.

Our model of respect begins with conversation. Our patient and public co-researchers helped us identify the importance of dialogue to share study information – and implications of participation – with PwD. Therefore we do so in a conversation with PwD and carer. They are able to continue this dialogue for two weeks prior to deciding about participation.

Thereafter, the research team maintains the conversation. We discuss with them advance preferences regarding participation as their condition progresses, but do not consider these fully binding ‘advance directives’, rather a means of elucidating present values. We also ask them at an early stage to nominate a consultee – friend, family member or carer whom they trust to engage with them in ways that support autonomy – to join this conversation. Through this effort to build a

supportive relationship, we aim to preserve decision-making participation of PwD. Regular check-ins allow us to understand how preferences and values are evolving, and confirm ongoing assent or respond to changes.

As deliberative and communicative capacities change, the ways in which this support manifests will too – as Smajdor argues, it requires that we take “the leap of faith” that PwD and their carers take every day, elucidating how whatever they are capable of communicating reflects what remains most important to them.

Conclusion

Asking what is valuable about autonomy shows that all of us, irrespective of capacity, depend on supportive relationships and an appropriate environment to articulate authentic decisions; and that most of us, even with impaired capacity, can hold and share some vision of the good. Clinical research needs to move beyond informed consent in operationalising respect for autonomy – not just for PwD, but for all.

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