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# Shared Decision-Making and Relational Moral Agency: On Seeing the Person Behind the ‘Expert by Experience’ in Mental Health Research

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*Abstract:* This focus of this paper is the moral and scientific value of ‘expertise by experience’, that is, knowledge based on personal experience of ill mental health as a form of expertise in mental health research. In contrast to individualistic theories of personal autonomy and the first-person in bioethics, my account of shared decision-making is focussed on how a relational approach to the ‘person’ and ‘patient values’ can throw new light on our understanding of ‘voice’ in mental health research. The mistake, I argue, is to think that a commitment to listening to the patient voice in the process of perspective taking implies a threat to ‘objectivity’ in clinical practice and the very concept of evidence in the philosophy of science more generally. Instead, I use Helen Longino’s account of epistemic validity in philosophy of science to argue that narrative experience and ‘patient perspective’ should be understood as an ongoing dynamic partnership working between the different stakeholders’ knowledge perspectives. I also address the connection between *expertise by experience* and the psychiatric significance of the *personal self* for the entrenched topics of agency, self-hood, personal identity, and self-knowledge in psychiatric diagnosis. In contrast to identity politics, my model of shared decision-making preserves a critical distance between perspective-taking and value itself in self/other appraisal as the gold standard for good clinical practice.

## 1. Introduction

This article uses aspects of my (Bergqvist, 2020) narrative particularist framework to critically explore the role of lived experience (sometimes referred to a ‘expertise by experience’) in mental health research and other mechanisms for patient empowerment and agency centred on quality of life and shared decision-making. In contrast to individualistic

theories of personal autonomy in bioethics,<sup>1</sup> my account is focussed on how a relational and co-creative approach to subjectivity and patient values can throw new light on our understanding of ‘voice’ in mental health research. First, by looking at the scientific impact of patients as stakeholder experts, implicit in the received notion of ‘expertise by experience’ (often abbreviated ‘EbE’) in mental health research, rather than on individual vulnerability to mental ill-health and responsiveness to categorical diagnostic measures and treatment involving predictive biomarkers, I show how patient voice in terms of agency and shared decision-making reframes the philosophical question of subjectivity in ‘lived experience’ and the problem of scientific validation in relational terms.

Concepts like ‘shared decision-making’ and ‘co-production’ entered the scene alongside that of ‘person-centred care’ and demarcates a renewed interest in patient values in an attempt to democratize the practice of psychiatry in giving people ‘voice’ over their own care and, to some extent, resources for what Gerrit Glas (2019) calls ‘self-management’. The theoretical and practical motivations for these concepts, alongside that of ‘person-centred care’ in health and social care more generally, were each concerned in different ways with restoring the patient to centre stage in healthcare. Importantly, however, in contrast to earlier autonomy-driven models of medical ethics such as Beauchamp and Childress (1989), the emphasis on the ‘person’ and the centrality of ‘patient values’ in these new person-centred concepts denotes a *particular individual person* in narrative terms (Bergqvist 2020, 2022). This difference is worth pause.

As noted by Fulford and Bergqvist (in press) earlier models of ‘patient values’ in terms of the principle of patient autonomy, scientific as well as ethical, the ‘patient’ was conceived as an abstract and generalized person standing in opposition to the equally abstract and generalized person of the ‘clinician’. In the new person-centred models, by contrast, the patient is a particular *individual person* engaging with a particular individual clinician (or individual team members) in a particular healthcare interaction. Ben-Moshe argues that although the ‘physician might be the expert when it comes to the patient’s medical good, it is the patient who has intimate knowledge of his perception of the good’ (2017, p. 15).

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<sup>1</sup> Social scientist Priscilla Alderson (1994) argues that while autonomy-driven approaches went some way to reinstate the importance of the person in medical science, medical ethics itself has developed into a new form of increasingly professionalised medical science rather than towards offering mechanisms for empowering patients. (See Fulford and Bergqvist, in press.)

Nonetheless, the decision is shared and, in this sense, ‘internal’ to medicine because the proper treatment outcome can be (jointly) determined only through the discussion between the clinician and the patient. On this model, the outcome does not stand apart from the clinical process, but is rather constitutive of it. Similarly, the particularist critique of traditional moral theory (in medical ethics and medical epistemology alike) derives from the rejection of the claim that the normative content of ethics and medical discourse be specifiable *in vacuo* independently of concrete circumstances of assessment and choice. Particularists like Jonathan Dancy (2004) hold that responsible moral thought and judgement do not require a suitable supply of general principles that can serve as a premise for the conclusion in an inference, whether explicitly or implicitly and no matter how sensitively done. Instead, and this is the positive claim that I defend (but do not argue for here), practical moral knowledge is claimed to be a form of knowledge that results from the successful exercise of moral *discernment* in particular contexts of evaluative appraisal (Bergqvist 2018a, 2018b, 2019; see also Lindemann, 2014). This mirrors recent developments in medical epistemology.<sup>2</sup> In particular, the so-called ‘biomedical model’ implied by the evidence-based medical paradigm has made significant impact on thinking and policy regarding clinical reasoning, promoting the application of research-evidence from randomised controlled trials to clinical decision-making (Evidence-Based Medicine Working Group, 1992; Sackett *et al.*, 2000). These developments have been accompanied by a renewed interest in narrative in bioethics (Lindemann, 1997, 2001, 2014) and medicine (Charon 2006; Charon *et al.*, 2008), casuistry (Tonelli, 2014), and other attributes of a whole, integrated decision-maker.<sup>3</sup> Sackett (2000) himself makes it clear that clinicians must utilize other forms of medical knowledge, including clinical experience, in order to arrive at the best medical decision for a particular client. As moral particularism rules out some of the most popular answers given by traditional ethical theories, a good starting point for an investigation into the question of what

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<sup>2</sup> For excellent discussion of certain key new methods for research and clinical care that have reshaped the practices of medical knowledge over the last forty years, see Solomon (2015).

<sup>3</sup> It is worth noting that proponents of Evidenced-Based Medicine and traditional bioethics of course recognize the need to ‘integrate’ specific features of cases into clinical reasoning. However, as emphasized in Tonelli (2014), much work remains to be done at the theoretical level on this issue, leaving the problem with practitioners who, despite the wealth of theory in the area, find they must work out for themselves what exactly it means to integrate these features across diverse cases.

an adequate justification of moral and clinical judgement can consist in is a confrontation with particularism, which forces us to widen the range of possible answers.

In what follows I will set to one side the complex question of cure in recovery-based models of shared decision-making to allow sharper focus on the interplay of *values* and *relational moral agency* in examining the implicit task of self-ownership in psychiatry.<sup>4</sup> The simple reason (which I develop in more detail below in section 2) for assenting to the relational claim about shared decision-making as a working partnership between the different individual stakeholders is that therapeutic success on associated models of recovery and person-centred management also involves complex existential issues surrounding self-ownership, personal identity, and responsibility in the recovery process, where the notion of self-ownership is also framed relationally as an ongoing mirroring process between self and others for the future (Jopling, 2000; Tekin, 2011; Bergqvist, 2018b).

On my view, what we need to avoid unhelpful dichotomies between the ‘personal’ perspective of lived experience as *expertise by experience* and ‘objective’ expert option is a better understanding of the idea of *point of view* in the dynamic ‘working partnership’ interplay between patient and clinician. I use this non-committal concept of ‘value’ and ‘perspective’ deliberately to avoid commitment to more loaded accounts of the relationship between the normative content of psychiatric discourse and practical moral agency, and the general notion of ‘deliberating from a point of view’ (Bergqvist, 2020, p. 157). To make this option visible, in section 2 below I discuss shared decision-making and draw on previous work (Bergqvist, 2020) of relational narrative structure in clinical judgement, where the concept of ‘narrative’ is to be understood as an interactive process of perspective-taking between patients and clinicians shaped by the context of their treatment setting. In section 3, I address the problem of asymmetry in stakeholder voice, power, and credibility between

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<sup>4</sup> I will also not discuss at length the growing literature on knowledge imbalance and epistemic injustice in received models of shared decision-making and co-production in addressing the real barriers, contingent practical challenges, and intrinsic theoretical obstacles to genuine co-production that does exist in this space (discussed at length in Wilde and Spencer & Kidd’s respective contributions to this volume). While there are pockets of good practice (see Harcourt & Crepez-Keay’s contribution to this volume), there is no general understanding and practice of co-production in research and knowledge exchange.

‘expertise by experience’ and ‘expertise by medical training’ in exposing the ways persons with lived experience of mental illness contribute as knowers based on their experience. I argue (section 3) that there is an irreducible normative aspect of knowledge in psychiatry and clinical practice, and further show how this prevents the slide from patient values and shared decision-making to both value relativism (as seen in Kingma and Banner’s 2014 discussion of values-based practice) and value constructivism (as in Ben-Moshe, 2017) in understanding the moral and scientific importance of lived experience in mental health research. Section 4 discusses the conceptual relationship between *expertise by experience* and the psychiatric significance of the *personal self* for the entrenched topics of agency, self-hood, personal identity, and self-knowledge in psychiatric diagnosis in addressing the issue of (mis)recognition, romanticism and (self-)stigma. This discussion raises the explanatory desideratum for the penultimate section 5: what, if anything, does the idea of representing others and oneself *rightly* mean in shared decision-making? I identify the challenge of self/other appraisal with the discourse of giving uptake (Austin, 1975) as a dynamic and open-ended relational dialogical process of self/other appraisal in concept application. I end with some concluding remarks about what this tells us about the relationship between the idea of expertise by experience and the wider task of self-understanding (Tekin, 2019) and re-configuration of personal values in the recovery process.

## **2. Shared Decision-Making**

The focus of my narrative philosophical approach to shared decision-making in mental health adopted here concerns the methodology of shared decision-making as the gold standard for good clinical practice in integrating the best evidence (what works best), professional experience, and stakeholder values – rather than treating the concepts of *expertise by experience* and *patient values* as something that must be reconciled with an ‘objective’ diagnostic approach and ‘clinical expert opinion’ in meeting the gold standard for health and social care. Shared decision-making of the kind that I am concerned with in this chapter is a procedural concept of decision-making in the service of patient empowerment and agency to facilitate recovery, *viz.* restoration of a quality of life from the point of view of the individual patient given their histories and situated ecological systems (Herring, Fulford *et al.*, 2017). It means decision-making, based on evidence and values, that is shared between the individual clinician (or clinical team members) and the individual patient involved in the particular situation in question (Bergqvist, 2020; Bergqvist and Fulford, in press). Importantly, the notion of ‘sharing’ values here implies precisely not a consensus model of ‘value agreement’

between the individual patient and the individual clinician (or clinical team members); ‘sharing values’ here denotes rather the open-ended dialogical process of the different stakeholders coming together with the shared aim of *reaching a decision* given the contextual parameters of the local treatment situation and the wider healthcare system in question.

Shared decision-making of this kind may be challenging in both its evidence base and its values base. Evidence-based practice provides a process that supports clinical decision-making where the *evidence* in question is contested (because complex and/or conflicting), i.e., a process that typically relies on statistical and computational methods such as meta-analyses of high-quality research data. Values-based practice, in turn, relies on a range of more practical process elements that build on learnable clinical skills that supports clinical decision-making where the *values* in question are contested (again because complex and/or conflicting).<sup>5</sup> But the principle of relying on *process* rather than prescribing outcomes is the same (Bergqvist and Fulford, in press). The result is a dynamic process of shared decision-making on integrating evidence and values in what Fulford *et al.* call ‘linking science with people’ (Fulford, Peile, and Carroll, 2012, p. 1). I do not here have space to discuss Fulford’s own model of values-based practice in detail, only note two salient parallels with its ‘science driven’ principle of values (see Fulford, Peile, and Carroll, 2015, chapter 12) and my narrative approach to expertise by experience in opening clinical decision-making to an ever-wider range of individual values in the very concept of evidence.

### *i) Partnership building*

Salient examples in psychiatry that centre on the individual historical person and their ecological context is found in associated models of recovery and person-centred management that is geared towards the restoration of well-being and re-engagement in major social, vocational, and family roles (RCPH, 2019; Maj *et al.*, 2020). This essentially relational concept expresses a working partnership between patient and clinician in a shared model of clinical decision-making. The relational concept of ‘working partnership’ between patient and clinician is also a central feature of what Annemarie Köhne (2020) refers to as the *relationalist turn* in psychiatry (a term used also in the recent enactivist works in the

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<sup>5</sup> Further information on values-based practice, including full text downloads of training materials, an extensive reading guide, and dedicated library resource is given on the website of the Collaborating Centre for Values-based Practice at St Catherine’s College, Oxford: [valuesbasedpractice.org](http://valuesbasedpractice.org).

philosophy of psychiatry by Sanneke da Haan, 2020, and that of critical psychiatry). This movement in psychiatry seeks to move away from essentialist descriptive psychopathology and many of its diagnostic kinds and classification systems such as the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and the *International Classification of Diseases* (ICD) to instead view diagnostics and treatment as a dynamic dialectical process such that the diagnostician and patient ‘co-create a patient’s diagnosis, and the therapist and patient co-create the therapeutic relationship that mediates change’ (Köhne, 2020, p. 136).

However, what is typically *not* addressed within relationalist psychiatry is the psychiatric significance of the *personal self* (Sadler, 2007) beyond that of identifying psychopathological categories and other ‘problems of living’ (Stein, 2021). As argued about psychopathology at length by Peter Zachar (2019) and in more recent critiques of critical psychiatry by Robert Chapman (2023) from what Sedgwick (1982) refers to a ‘psycho politics’, an important aspect of ‘expertise by experience’ transcends the psychiatric symptoms space of descriptive psychopathology. I return to this claim in section 4 below. As Peter Zachar (2021) expresses the point in a recent commentary on Köhne (2020), because psychopathology never exists on its own, in addition to transcending symptoms, relationality in clinical practice sometimes requires transcending psychopathology itself, in as much a ‘psychopathology is a feature of persons who are embedded in communities, cultures and history’ (Zachar, 2021, p. 143). As I have argued elsewhere (Bergqvist, 2020, 2022), because there is no such thing as a ‘patient’ *in vacuo* from the particular treatment context within which that concept operates, an essentially relational partnership model requires seeing the *person* behind general diagnostic categories.

Psychological differences between persons can be revealed through narrative structures in a way that matters for the provision of effective treatment and management. As Solomon (2015) emphasises, narrative reasoning is also motivated by distinctly first-personal concerns that are operative in the practitioner-client *relationship*. I hold that the dynamics of that interpersonal relationship are part and parcel of what it means to address the patient’s needs to be seen *as* a person in empathetic care – without thereby reducing truth to an individual person’s perspective to encourage positive transformation.<sup>6</sup> (I return to this below in section 3, and further defend this claim in Bergqvist, 2022.)

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<sup>6</sup> Here I side with Goldie (2012) and Solomon (2015), who warn against confusing the notion of autographical narrative (clinical or otherwise) with its intentional object.



*ii) Assets focus*

In Bergqvist (2018b, 2022), I argue that the notion of empowering narratives to encourage positive change is a central concept behind the emphasis on the critical role of empathy in explaining human development and psychoanalytic change within the self-psychology tradition but is also key to recovery-based models of the significance of person-centred *quality of life* in medicine more generally. This is defined in mental health as recovering a good quality of life as determined by the values of (by what matters or is important to) the individual concerned (Allott *et al.*, 2002; Fulford, 1989, 2004, 2012). The importance of strengths in this regard was reflected for example in the UK government programme on values-based mental health assessment. The *3 Keys* programme, as it was called (National Institute for Mental Health in England, NIMHE, and the Care Services Improvement Partnership, 2008), identified three shared ‘keys’ to good practice in mental health assessment: three things that were identified in a wide-ranging consultation as being important alike by health professionals of all kinds and by ‘service users’ thus understood as patients and carers (Fulford *et al.*, 2015a, 2015b). The third of these keys was defined in the subsequently published Good Practice Guidance, as ‘a person-centred focus that builds on the *strengths, resiliencies and aspirations* of the individual service user as well as identifying his or her needs and challenges’ (NIMHE, 2008, p. 6); and the guidance included a number of real-life case examples of best recovery practice reflecting this aspect of mental health care (Slade *et al.*, 2014).

While there are research development reports on what in the United Kingdom is known as Patient and Public Involvement (PPI) and Expertise by Experience (EbE)<sup>7</sup> in mental health research to support both principles of shared decision-making that I have called (i) ‘working partnership building’ and (ii) ‘assets focus’, what guides the design of shared decision-making, and indeed the inclusion of those with lived experience in mental health care design and treatment methodologies in a public mental health approach, is nevertheless dependent upon mediation of differing values. Mental ill health is commonly cited as being largely caused by social factors, and accordingly, individuals and differing social community groups prioritise different values and goals dependent upon their experience. Person-centred

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<sup>7</sup> Other cognate terms to that of ‘PPI’ and ‘EbE’ (that are *not* equivalent in meaning) found in the literature surrounding shared decision-making include ‘experience-based co-design’ (EBCD), ‘service-user engagement’, ‘participatory research’, ‘action research’, ‘user-led research’, ‘survivor-led research’ – to name but a few.

medicine purports to offer ways of competing values being accommodated, and a number of values-based practice guides exist, offering practical support for clinicians adopting a values-based approach. However, clinicians and those with lived-experience often disagree, which leads to debates around values and how best to proceed with preventative and recovery-focused interventions. For instance, how should public mental health accommodate the positive experience reported by many with the lived experience of a severe and enduring mental illness (SMI) of their symptoms? Philosophers have contributed to the debates surrounding the ‘Mad Activism’ movement (see, e.g., Rashed, 2019). Other important questions, discussed at length by Sofia Jeppsson’s and Zsuzsanna Chappell’s contributions to this volume, concern the even harder question of what it is permissible to value as an ‘expert by experience’ based on one’s one personal experience of mental health challenges and/or illness.

One option in understanding the process of shared decision-making in navigating such differences in mediating conflicting value perspectives internal to a positive procedure that would satisfactorily incorporate ‘the patient voice’ is to follow Ben-Moshe’s (2017) constructivist account of the *ethos* of humanistic (mental) health and care. On this view, which I articulate in Bergqvist (2020), shared decision-making is achieved through an interactive dialogue where doctors are considered the clinical experts on how conflicting treatment outcomes will impact the patient, and the patient as having the knowledge of the degree to which they value those outcomes. As Ben-Moshe (2017, p. 1) puts it, ‘patients should be involved in the construction of medicine’s morality not only because they have knowledge that is relevant to the internal morality of medicine— namely, their own values and preferences – but also because medicine is an inherently relational enterprise: in medicine the relationship between physician and patient is a constitutive component of the craft itself’. This, I maintain, is also the key normative element of the shared decision-making model that requires clinicians to make value judgements with the active participation of the patient in dialogue: the sources of normativity are internal to the dynamic process of interaction with patients, where the interaction between patients and clinicians is understood relationally as an open-ended process of perspective taking informed by the wider treatment context.

Where I depart from Ben-Moshe is in my standing commitment (not argued for here) to moral realism rather than moral constructivism in understanding the central internal normative requirement of shared decision-making as the gold standard for good clinical practice. My particularist narrative approach also works with a stronger moral realist notion

of ‘value’ than the idiosyncratic perception and personal ranking of preferences (Ben-Moshe, 2017) and the non-committal construal of the concept of value as ‘what matters to you’ that is given on Fulford’s procedural values-based practice. I argue that it is a mistake to think that a commitment to moral realism implies a commitment to stance-independent views of ‘objectivity’ in clinical practice (as in Pellegrino, 2001a, 2001b) and philosophy of science more generally as the only option in understanding the idea of mind-independent value in good medical practice. Instead, we may follow Helen Longino (1990) and Arthur Fine’s (1986) accounts of epistemic validity in philosophy of science and think of discernment in relational terms such that there is no ‘outside’ in shared decision-making.

### **3. Science as Social Knowledge and the Problem of Asymmetry in ‘Expertise by Experience’<sup>8</sup>**

In the previous section (§2), I suggested that the slide from patient values and shared decision-making to both value relativism and value constructivism seems tempting due to the implicit mistaken assumption that realist arguments about clinical understanding must be construed from a perspective outside clinical practice (and the ‘working partnership’ between different stakeholders there in play). Rather than thinking of narrative in this way, John McDowell suggests a new test of narrative validity as determined from within an engaged scientific practice. He writes:

Like any thinking, [narrative] thinking is under a standing obligation to reflect about and criticize the standards by which, at any time, it takes itself to be governed. [...] Now, it is a key point that for such reflective criticism, the appropriate image is Neurath’s, in which a sailor overhauls his ship while still afloat. This does not mean such reflection cannot be radical. One can find oneself called on to jettison parts of one’s inherited ways of thinking; and, though this is harder to place in Neurath’s image, weaknesses that reflection discloses in inherited ways of thinking can dictate the formation of new concepts and conceptions. But the essential thing is that one can reflect only from the midst of the way of thinking one is reflecting about. (McDowell, 1994, p. 81)

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<sup>8</sup> This section relies on my previous arguments about narrative formulations and the problem of relevance found in Bergqvist (2020, pp. 156–8).

Thus, on this view, while the test for validity in narrative formulation is in the end a matter of judgement, it is nonetheless a judgment made against general patterns of what makes rational sense from within an engaged practice – and all such concepts are continuously subject to critical scrutiny from the ‘space of reasons’ (McDowell, 1994). To see this, we may follow Fine’s (1986) discussion of adopting a ‘natural ontological attitude’ in the domain of philosophy of science. Fine writes:

The realist, as it were, tries to stand outside the arena watching the ongoing game [of science] and then tries to judge (from this external point of view) what the point is. It is, he says, about some area external to the game. The realist, I think, is fooling himself. For he cannot (really!) stand outside the arena, nor can he survey some area off the playing field and mark it out as what the game is about. (Fine, 1986, p. 131)

Despite Fine’s rejection of traditional epistemological realism, he does not support a form of epistemological anti-realism. The claim is rather that the reasoning motivating both the traditional realist attempt to validate scientific reasoning and anti-realist efforts at undermining it fails, since it is impossible to take the sort of external perspective in science that these arguments seem to require. As emphasized by Nancy Cartwright (1999, 2009), the concern about external validation is not only a concern for narrative formulations and the medical humanities; *any* discipline where correctness is at issue requires background knowledge, presuppositions, and reliance on an acquired sense for what matters and when. As a result, on the assumption that the criterion of (value-neutral) empirical adequacy is the least defensible basis for assessing theories (if such a criterion is available at all), Longino (1990) further argues that a pluralism of stakeholder perspectives and diversity in ‘expert voice’ is *necessary* for scientific inquiry. Precisely because there is ‘no outside’ in scientific inquiry as a social enterprise, such diversity in knowledge-perspectives is necessary, Longino (1990) argues, to identify blind spots and problematic assumptions built into any scientific theory, methodology, or approach within a given knowledge domain. In Bergqvist (2020), I also note analogous methodological developments in prominent strains of social epistemology in philosophy of science, which seek to integrate descriptive modalities found in sociology and anthropology into the study of science more generally. Indeed, as Holman, Bernecker, and Garbayo (2018, p. 4359) note, a central reason why philosophers such as Goldman (1999), Solomon (2001), and Longino (1990) endorse the methodological reliance on detailed case studies (a focus on the particular) in philosophy is their acknowledgment

‘that traditional approaches to philosophy of science were not well-grounded in the realities of scientific inquiry.’

Now, one such *specific* aspect of the *reality* of psychiatry as a specialist discipline of medicine is the social dimension of knowledge found in the *asymmetry* in stakeholder voice, power, and credibility between ‘expertise by experience’ and what we may think of as the contrastive concept of ‘expertise by professional training’ in exposing the ways persons with lived experience of mental illness contribute as knowers based on their experience. As argued at length by Mohammed Rashed (2019), the continuous debate over psychopathological classification within mad studies show that knowledge-creation within psychiatry as a discipline is an inherently value-value process: there is no neutral vantage point between psychopathology and the mental health survivor activist movement in determining whether someone classifies as ‘mentally ill’ or is better described as facing ‘problems of living’ (Stein, 2021) or, when a given psychopathological concept is deemed to apply, what should be done about it in managing the condition in question.

Moreover, Rashed (2019, p. 38) notes that, in the UK context of employment rights and reasonable adjustments in the workplace, resistance to a more equitable *horizontal* (rather than asymmetric) model of co-production has come from both sides applying the social model of disability to mad studies in articulating the controversial concepts of ‘mental disability’/‘impairment’ and the less loaded concept of ‘variation’. Rashed writes:

Some psychiatric survivors/service users refuse to be associated with disability discourse as they do not consider themselves to have an impairment, nor do they want to be associated with the “pathologizing” implications of the term impairment [...]. Conversely, others actively endorse the term disability as it creates a sense of community across the survivor/service-user/mad and disability movements [...]. Some are reluctant to use “disability” for fears of being accused that they are not disabled enough; that they do not have life-long impairments. (Rashed, 2019, pp. 37–8)

Let us take stock. Returning to Longino’s (1990) argument about scientific validation as a social enterprise, on the assumption that the criterion of empirical adequacy is the least defensible basis for assessing theories (if that criterion is available at all), one may argue that the voice of ‘expertise by experience’ must be taken into account on the grounds that there is a *requirement* to seek out a plurality of other stakeholder voices in mental health research

beyond that of the ‘expert medical opinion’. While I am not in a position to defend this claim here, taking a leaf from Rashed’s reading of the work of Axel Honneth (2007) on shame and (self-)stigma in the ethics of recognition – i.e., ‘how can this person transition from drowning in a sense of shame [for *who he is*] to demanding that you accept him for who he is?’ – a possible answer to our asymmetry dilemma is found ‘in the discourse of civil rights’ (Rashed, 2019, p. 102). Similarly, if indeed there is no neutral knowledge-perspective for drawing the line between what is a psychopathological ‘mental disability’ and what is not, we may also speculate that the debate over ‘mental disability’ in the discourse of survivor activism needs to be settled further downstream in addressing employment rights and reasonable adjustments in the workplace.

Now, according to intersubjectivity theorists like Chris Jaenicke (2008) and Donna Orange (2002), there are two parts to the implicit corollary that there is ‘no outside’ in understanding the value-laden nature of knowledge in psychiatry and psychotherapy. I will look at these briefly as both are relevant to best practice in mental health. The first claim is an epistemic ‘no priority’ claim about knowledge in intersubjective empathetic inquiry, whereby neither perspective of the parties involved in the therapeutic relationship is prioritized over the other. This is clearly relevant to shared decision-making and co-production as best practice in integrative and person-centred health care that is geared towards recovery and quality of life (Maj *et al.*, 2020) mentioned earlier (section 2). On this view in psychotherapy, as I argue in Bergqvist (2018b), therapeutic inquiry does not assume that the clinician’s perspective is more apt than the patient’s or that we can directly know the perspective of the patient. As Stolorow expresses the point in psychoanalytic psychotherapy research, we can only ‘approximate this reality [of the other] from within the particularized scope of the analyst’s own perspective’ (Stolorow, 1999, p. 385). The second claim is a claim about the meaning of individual concepts as a function of the wider interpersonal systems in which they operate (in psychoanalytic discourse and beyond). For psychotherapist Donna Orange (who defends a version of constructive internal realism), the core problem with failing to recognize the normativity of concepts in their contexts is that we may mistakenly come to believe that it is possible to describe, context free, ‘what the patient is doing to me, or I to the patient, as if one or both of us could momentarily stand outside the system that we constitute together’ in the psychoanalytic process (Orange, 2002, p. 698). Each of those perspectives may be more or less appropriate, depending on the task at hand and given the wider contextual parameters of the treatment situation (and wider health care systems).

I differ from Orange, Stolorow, and Jaenicke in my denial that the emphasis on perspective and point of view in shared decision-making commits us to constructivism rather than realism in understanding the nature of meaning and value itself. I maintain that we need to be careful not to confuse the general idea of upholding some notion of ‘clinical expertise’ (which some argue involves a prerequisite asymmetry between the clinician and the patient in the therapeutic relationship, see Jaenicke, 2008, p. 14) with a misguided idea of neutrality. What I mean by this is that we must also recognize the challenges that the necessity of relatedness places on individuals within the clinical commitment to the joint epistemic and political endeavour for positive change and recognition. However, understanding the general discourse of ‘perspective’ need not imply a special class of agent-relative values (as in Nagel, 1986). We can also think of *point of view* as an agent’s standpoint on independent reality (evaluative or otherwise). This raises a number of meta-philosophical questions concerning the relation between point of view and the notion of non-perspectival value. If the notion of non-perspectival value is better understood in metaphysical realist terms, does it not follow that the concept of perspectival value is value that metaphysically depends on human perspectives and worldviews for its existence? No. We can talk of perspectival value in different ways. It might mean that value is fixed by our actual perspectives and worldviews, whatever those happen to be. This would lead to a highly subjectivist picture. But, as I have argued elsewhere (Bergqvist, 20018a, 2019), there is space for an alternative view according to which value would not exist but for creatures with perspectives and worldviews, but actual perspectives and worldviews can be mistaken. Such perspectival value is ‘for us’, and we can be better or worse at detecting it in realistic and continuous self-cultivation in concept application as a relational and historically situated endeavour (Bergqvist, 2019, p. 224).

To make this option visible in the present context about the significance of ‘expertise by experience’ in mental health, I again emphasise that my relational concept of narrative structure in experience is to be understood as a dynamic, interactive, and open-ended process of perspective-taking between different stakeholders shaped by their treatment setting and other contextual parameters and structures (such as background health care systems). It is this last claim, combined with Rashed’s important (2019) work on identity (mis)recognition (and, more broadly, the discourse of civil rights), that illuminates the allusion to value-blindness in Longino’s (1990) argument that the scientific assessment of theories *requires* a plurality of knowledge-perspectives to identify blind spots and problematic assumptions built into any scientific theory, methodology, or approach. For on this view, communicating across different perspectives found in intersubjective encounters can serve as a crucial corrective to

being overly committed to *‘the voice’* of the prevailing norms and ways of seeing the world – in clinical contexts and beyond (Bergqvist, 2022, p. 486). This raises the new question of what makes it *right* to say that use of a given concept in public discourse in the appropriate one on a given occasion.

#### **4. The Problem of Romanticism and the Psychiatric Significance of the Personal Self**

A corollary of Longino’s (1990) interest in social conventions in science of relevance to our discussion of the moral and scientific value of ‘experience by experience’ in mental health research generally is the recognition that even the most open-minded theorists, when presenting themselves as studying specific issues in each scientific domain, are in fact always relying on background beliefs about the world. What still needs explaining is a way in which agents could, as Iris Murdoch once puts it, ‘see different worlds’ (1956/1998, p. 82) in shared decision-making as a mechanism for recognition.

As noted by Edward Harcourt (2016, p. 86), while ideals can support self-appraisal that is both realistic and ongoing, one concern with idealisation is that ‘the romantic use’ of fictional models mitigates against the continuous task of seeing things aright; another danger with romantic self-appraisal is that it obfuscates opportunities for self-cultivation in appraising the ideals in a healthy way. Here is the problem. Even if we grant that narrative understanding and self-experience are not easily separated in empathetic engagement and the search for interpersonal connection and intra-psychic integration, there remains the possibility of outright distortion and unintentional misrepresentation, self-deceit and, importantly, disavowal in relating, in a first-personal way, to aspects of one’s life (Goldie, 2012; Harcourt, 2016; Schechtman, 2016; Bergqvist, 2018b). To borrow a helpful image from Richard Moran, part of the problem in creating opportunities for self-cultivation in concept application is that ‘the fate of situatedness as such is not escapable’ (Moran, 2012, p. 190). And yet, returning to the aforementioned challenge of (mis)recognition and responsibility (see section 4), we must at the same time acknowledge that individual thought and judgement is not thereby confined to commonly articulated concepts and familiar ideas in line with the default ‘social conventions’ of one’s moral situation (Bergqvist, 2019, pp. 220–1). This concern, it seems to me, is also part and parcel of Lisa Tessman’s (2005) and Havi Carel’s (2017) pessimism about the power of self-examination to transform us on certain non-pluralistic virtue theoretical accounts of virtue and the idea of flourishing in illness. (For more about the general notion of moral transformation in illness, see e.g., the works of Brady 2018, 2021; Carel, 2018; McMullin, 2019; Tessman, 2005). In what follows I examine



romanticism in connection with recognition and (self-)stigma in mental health in understanding the psychiatric significance of the personal self in psychiatric diagnosis (Sadler, 2007) and, with it, broader political discourse concerning the ethics of identity (mis)recognition in realistic self-appraisal.

Psychiatric diagnosis serves many functions in the struggle for recognition, including access to public mental health systems and legal compensation, but it is not necessarily well equipped for the task of self-understanding (Tekin, 2019) and re-configuration of personal values in the recovery process – and the likelihood of optimal outcome that is geared to the individual person’s quality of life (May *et al.*, 2020). Patients who are diagnosed with a serious and enduring mental health condition often find it difficult to make sense of themselves in relation to their psychiatric diagnosis (Bergqvist, 2021). Specifically, they have problems with distinguishing their ‘self’, or ‘who they are’, from their mental disorder or diagnosis (Radden, 1996; Sadler, 2007; Dings & Glas, 2020; Carls-Diamante, 2022; Porter, 2022). Accordingly, several authors in this volume address the scientific value of *expertise by experience* in relation to the growing philosophical literature of self-diagnosis (see Sam Fellowes). Call this the *transformative* dimension of (mis)recognition in the complex journey from diagnosis to self-ownership in the doctor-patient relationship. Consider Gilardi and Stanghellini’s (2021) dialogical reflection on the importance of relational narrative identity and dynamic therapeutic empathy at play between the person in psychiatric treatment of schizophrenia (which they argue is key for patient empowerment and recognition):

Drugs don’t cure. Meaningful relationships do. The recognition I got was instrumental in my own taking possession of my condition, and in delivering the same recognition for the people around me, starting from my mother and then everyone else. (Gilardi and Stanghellini, 2021, pp. 7–8)

Interestingly, as Rashed (2019, p. 102) notes, even on Honneth’s (2007) critical theory discourse approach to the paradox of misrecognition alluded to earlier (section 3) – i.e., ‘how can this person transition from drowning in a sense of shame [for the “schizophrenic” *who he is*] to demanding that you accept him for who he is?’ – there is nonetheless an important normative implication that some empirical requirements for psychological health are also moral goods. Rashed writes:

Implicit in Honneth's account is the idea that being loved, being respected, and being esteemed are desirable states. We can argue that any reasonable conception of psychological health must include an adequate realisation of these three states. If so, then recognition plays a key role in our psychological health as one key empirical condition. From there, it is only a short step to its converse: misrecognition can impair our psychological health (Rashed, 2019, p. 102).

On the working model of knowledge as a social enterprise, Rashed continues, one possible way forward in understanding such empirical requirements for psychological health – love, recognition, respect – as also moral goods is again found in social relations for Honneth. As Rashed puts it, given that recognition as a condition for psychological health is 'a desirable state for the individual' whereas misrecognition is 'a threat to its realization at the level of social relations', it is perhaps not a surprise that 'Honneth (e.g., 1996) describes situations where social relations result in psychological harms of this kind as social pathologies that we ought, in some way, to socially and politically address' (Rashed, 2019, p. 102).

What my account adds to this idea is that, while such choices are revelatory or expressive of a distinctly first-personal psycho-political stance on the usefulness of the concept of mental illness, they do not constitute or *determine* self-hood and self-interpretation in a fixed way. Instead, on my use of the idea of narrative structure in self-understanding, the relevant sense of 'narrative' is instead treated as what I have in other work called a 'transcendental condition' for judgement (as expressive of one's agency and self-conception), as opposed to a feature of the object of evaluation itself (Bergqvist, 2020, p. 152).

## **5. Towards an Integrated Approach**

A structurally similar worry about an overly atomistic conception of the self is found in contemporary discussions of perspectival realism in the psychological literature. Addressing the issues of reality and truth in empathetic enquiry, Donna Orange (2002) discusses a range of divisive and misleading dichotomies in differing schools of psychoanalytic thought.<sup>9</sup> Orange argues that each side of the perceived bifurcation is typically seen as more fundamentally real in each school of thought: where Freudians and Kleinians are described as prioritising the internal and the conflictual, self-psychologists emphasise developmental

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<sup>9</sup> My discussion of this example draws on my previous argument on the importance of the idea of *uptake* in psychiatric ethics in Bergqvist (2022, pp. 487–9).

deficits and reject drive theory-generated conflict; interpersonalists, in turn, supposedly have a bias for the external here and now in the therapeutic process, treating other factors as secondary and defensive. Taking her cue from Hans-Georg Gadamer's (1991) hermeneutic ontology in her work on emotional understanding and, in particular, the empathetic process of attunement in psychoanalytic understanding, Orange argues that the target concepts of the relevant dichotomies are themselves part of wider intersubjective systems of meaning, systems outside which the very metaphor of the target concepts lack clear sense. I here take no stand on whether the analysis of specific schools of psychoanalytic theory is adequate *per se*. What matters for my present purposes in relation to the theme of relational self-cultivation in psychiatric ethics is the deeper claim about adopting the so called 'perspectivist attitude' (Orange, 2002). Orange writes:

The question is not here-and-now versus then-and-then, nor is it conflict versus deficit. Rather, it is recognising with Gadamer that everything is past-loaded, that we converse and inquire within a conversation that is in part created by us, but within which we find ourselves. We are inside the conversation, which is itself always further embedded in larger cultural (political, racial, sexual, and so on) contexts. There is no outside. (Orange, 2002, pp. 698–9)

The central idea here is one of recognising the metaphorical quality of concepts in their contexts in understanding other points of view and, in particular, responsiveness and openness to the differences and vulnerabilities of others in securing understanding in a therapeutic conversation. Such pluralism in communication in meeting with other points of view in open-ended dialogue is one of humility and curiosity, rather than polarised conflict. By championing a philosophical approach to the co-production of research that is also reflexive and explorative, one key methodological strength is thereby a solution to psychiatry's 'othering' problem of how to integrate 'the lived experience' or 'service user voice' in shared decision-making and research design. For on this view, communicating across differences in the entrenched 'veiled' social world operative in pathologized interpersonal encounters in an explorative dialogue can serve as a crucial corrective to being overly committed to the prevailing norms and ways of seeing the world (see King, Fulford, and Bergqvist, 2020, p. 32). I have elsewhere argued (Bergqvist, 2018b) that this idea is helpfully understood in relation to Austin's (1975) notion of giving uptake as a form of ethical achievement, a professional virtue if you like. Nyquist Potter (2009) elucidates the

applicability of Austin's idea of uptake in linguistic communication in mental health as the claim that there is a distinctive ethical dimension to communication in clinical practice that involves having the right sort of attentiveness to particulars, which explicitly moral general concepts such as 'respect' and 'dignity' fail to capture.<sup>10</sup> Nyquist Potter writes:

All of us perceive, reason, and evaluate through conceptual schemes that are embedded in socially situated norms. So, for clinicians to fully embody the values and commitments of medical practice [such as values of respect, autonomy, dignity, benevolence, non-exploitation], they will need to extend their ethical framework. Learning to give uptake is an instance of ways that clinicians need to stretch themselves morally and, because uptake is a virtue, it is part of what is involved in living well. (Nyquist Potter, 2009, p. 144)

A central feature of giving uptake rightly, then, is the ability to communicate across differences in salient entrenched conceptual schemes that are operative. It is an open-ended communicative process which is described as 'ethical' because it also serves as 'a crucial corrective' to the default tendency of being overly committed to prevailing norms and ways of seeing the world (Nyquist Potter, 2009, p. 144) *from the communicator's position* – in ways that may require that we 'set aside preconceived ideas about value and meaning' in taking seriously the reasons that a person gives for her actions and beliefs (Nyquist Potter, 2009, p. 141).

The challenge that arises from the plurality of perspectives highlights an aspect of the moral difficulty of uptake in seeing the reality of others (and oneself) aright, something that I maintain is also key in re-appraising relationality as a tool in clinical contexts and, where necessary, empowerment for positive change. The mistake, I argue (Bergqvist, 2020), is to think that a commitment to moral realism in psychological self-appraisal implies a

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<sup>10</sup> As I read her, Potter Nyquist's argument about framing uptake in terms of virtue is neutral on the meta-ethical question as to whether the conventional norms of Austin's speech act theory could also be said to ground or constitute genuine moral facts. According to Terence Cuneo (2014), moral facts are among the prerequisites of our ability to perform illocutionary speech acts, such as asserting, promising, and commanding. Consequently, if there are no moral facts we do not *speak*, in the sense that we do not perform ordinary illocutionary speech acts.

commitment to stance-independent views of ‘objectivity’ in the philosophy of science more generally as the only option in understanding the idea of mind-independent value in good medical practice. Instead, we may think of discernment in relational terms such that there is no ‘outside’ in the application of shared concepts in clinical practice. That the resulting account preserves a critical distance between perspective-taking and value in the model of shared decision-making as the gold standard for good clinical practice is, I claim, a key advantage of my account over the popular idea of self-hood or personhood as identical with or constituted by autobiographical narratives. And the reason is that one can also adopt a second-personal stance on one’s own experience and address oneself, where the relationship between the first- and the second-personal narrative perspective on experience and self-understanding is itself a dynamic and open-ended evaluative process. I end with some concluding remarks about what this tells us about the question of language in the paradox of (mis)recognition with which we started.

## **6. Concluding Remarks**

In this paper, I have discussed the moral and scientific value of ‘lived experience’, that is, knowledge based on personal experience of ill mental health as a form of expertise in mental health research. In contrast to individualistic theories of personal autonomy and the first-person in bioethics, my account is focussed on how a relational approach to the ‘person’ and ‘patient values’ can throw new light on our understanding of ‘voice’ in mental health research. The mistake, I argued, is to think that a commitment to listening to the patient voice implies a threat to ‘objectivity’ in clinical practice and the very concept of evidence in the philosophy of science more generally. Instead, I followed Helen Longino (1990) and Arthur Fine’s (1986) accounts of epistemic validity in philosophy of science and argued that narrative experience and ‘patient perspective’ should be understood in relational terms such that there is no ‘outside’ in shared decision-making.

What is missing in accounting for shared decision-making in understanding the moral and scientific importance of lived experience in mental health research as a social enterprise is a relational account of the person and the wider diagnostic treatment context in understanding the process of perspective taking. Such reorientation of focus makes available a distinctive conception of ‘expertise by experience’ as a form of knowledge based on lived (first-personal) experience of mental health challenges, in which claims to objective meaning in patient narratives are criticized not as false *per se*, but as failing to yield the insight into the

problem it was the point of those claims to provide. The reason for this is that, on the new model, the voice of ‘lived experience’ is no longer understood in polarised contrast with the voice of ‘clinical expert opinion’ but as an ongoing dynamic partnership working between the different stakeholders.

Another dimension of the emphasis on patient narratives and lived experience in the philosophical literature (discussed in section 4) is the connection between *expertise by experience* and the psychiatric significance of the *personal self* for the entrenched topics of agency, self-hood, personal identity, and self-knowledge in psychiatric diagnosis. Here and elsewhere (Bergqvist, 2019), I have suggested that what marks out an ‘owned’ and, conversely, ‘disowned’ experience as such is the wider context of the subject possessing it seen as a *whole person* as characterised by a sense of oneself as an agent (Marcel, 2003). A variety of phenomenological and theoretical considerations strongly suggests that the psychiatric significance of the concept of selfhood is helpfully understood holistically by the five aspects of agency, identity, trajectory, history, and perspective that give us the sense of unity and control that generates the subjective sense of self (Neisser, 1988; Sadler, 2017). Although there are a few proposals in the psychological literature about therapeutic integration that resemble this claim (Freud, 1914; Radden, 1996; Tekin, 2011, 2019), few have made a general case in philosophy of psychiatry for thinking about *values* in understanding the psychiatric significance of the personal self in this way. My work is intended as a crucial step in that direction.

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