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Interactions between persons—knowledge, decision making, and the co-production of practice

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Interactions between persons – knowledge, decision-making and the co-production of practice

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Philosophy Thematic Edition 2019: Editorial Introduction

Title: Interactions between persons – knowledge, decision-making and the co-production of practice

(Short title: Interactions between persons)

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Abstract:

There is now broad agreement that ideas like person-centred care, patient expertise and shared decision-making are no longer peripheral to health discourse, fine ideals or merely desirable additions to sound, scientific clinical practice. Rather, their incorporation into our thinking and planning of health and social care is essential if we are to respond adequately to the problems that confront us: they need to be seen not as "ethical add-ons" but core components of any genuinely integrated, realistic and conceptually sound account of healthcare practice.

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Interactions between persons – knowledge, decision-making and the co-production of practice[1]

There is now broad agreement that ideas like person-centred care, patient expertise and shared decision-making are no longer peripheral to health discourse, fine ideals or merely desirable additions to sound, scientific clinical practice.[1-7] Rather, their incorporation into our thinking and planning of health and social care is essential if we are to respond adequately to the problems that confront us: they need to be seen not as "ethical add-ons" but core components of any genuinely integrated, realistic and conceptually sound account of healthcare practice.[8-13]

As reported in the most recent philosophy thematic edition of this journal,[14] researchers are rising to this challenge, to develop accounts of these key ideas with substantive import and application. To do so effectively requires not only extensive empirical work to understand and adequately characterise perspectives previously ignored or marginalised,[15-23] but also a fundamental conceptual shift in our understanding of the nature of and relationships between knowledge, evidence, value, patient experience and the social context of care, as well as the social context of research and all forms of knowledge production. [24,25] Put in economic terms, this shift requires a movement away from construing care as something provided to patients by professionals, and towards a model of partnership or co-production[26-28]: "the design, delivery and evaluation of services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours".[29]

The project to transform these core ideas from "rhetorical aspirations" to established practice will require the collaboration not only of theorists and empirical researchers, but also of practitioners, patients, family carers and representatives of the broader communities affected.[30-35] The dialogues we need to have are beginning, but they are by no means complete. As some of the contributions to this edition make clear, there are unresolved questions, generating on-going debate, about how best to make meaningful dialogue possible, who needs to be included and who *should not* be included, as well as about how to respond to the limits upon these developments placed by broader social, economic and political norms.

The clinician Stephen Henry noted in the first philosophy thematic edition of this journal that:

"Clinical medicine involves interacting with and understanding persons, and thus addresses a problem that is fundamentally different from and conceptually more complex than the kind of reasoning involved in problems such as mathematical calculation or measuring the masses of chemical isotopes."[36]

This, the tenth philosophy thematic edition of the journal, presents papers conducting urgent research into the social context of scientific knowledge and the significance of viewing clinical knowledge not as something that "sits within the minds and bodies"[37] of researchers and practitioners, but as a *relational* concept, the product of social interactions. It includes papers on the nature of reasoning and evidence, the on-going problems of how to 'integrate' different forms of scientific knowledge with each other as well as with broader, humanistic understandings of reasoning and judgement, patient and community perspectives.[37-48] Discussions of the epistemological contribution of patient perspectives to the nature of care, and the crucial and still under-developed role of phenomenology in medical epistemology,[49-51] are followed by a broad range of papers focussing on shared decision-making, analysing its proper meaning, its role in policy, methods for realising it and its limitations in real-world contexts.[52-77]

Knowledge, communication and informality: judgement and evidence in context

It seems almost too banal (perhaps even tautological) to point out that all practice, all research, all knowledge and indeed any human activity, takes place within a social context. As Wittgenstein noted,[78] even the private speculations I share with no-one are only possible because I have learned a public language. Yet, as debates about the nature of medical reasoning, evidence-based healthcare and clinical ethics have demonstrated, we are inclined

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1   With thanks to Nicola Blunden and Gideon Calder for bringing the concept of co-production to the editor's attention.

to adopt too abstract a view of knowledge and reasoning, to focus on formality and precision and ignore the importance of interaction, the context of communication, interpretation and the informal negotiation of meaning.

The edition opens with a paper by Dominic Hurst and Trisha Greenhalgh, which begins by noting that literature aimed at improving health practices tends to focus on propositional knowledge, adopting a model of decision-making in which "knowledge sits within the minds and bodies of healthcare workers".[37] They contrast this model to practice theories that "de-centre knowledge from human actors, instead situating knowing in the interactions between all human and non-human actors". Analysing extensive evidence of video recordings in two dental practices, they develop and defend an account of knowing in clinical practice as "a collective bricolage – using the actors' respective embodied knowing to generate and solve problems together". The "ecological" account of practice they defend has implications for the most effective ways to improve practices, challenging traditional models of decision-making in which "the professional is often the only one conceived as bringing (a usually "scientific") knowledge to an encounter".

Their paper is followed by a timely reminder of the social context of systematic research and review. Morten Sagar and Isabella Pistone begin by noting that the evidence-based medicine (EBM) movement has generated a rapid growth in reviews of research literature, with systematic reviews becoming more common in a wide range of professions, including education, public health, and social work.[38] The systematic methodology of the review can conceal the "interplay of informalities" underlying the research, generated by complexities and controversies regarding disciplinary methods, stakeholder values and other processes "not detailed in the formal descriptions of methods or reporting of reviews". The authors illustrate their point with a thorough analysis of a scoping review conducted by the Public Health Agency of Sweden on suicide prevention interventions. While it may be tempting to see literature reviews as formal, step-by-step procedures for surveying the available evidence, this obscures the informal negotiations and unpredictability of any complex review.

Sasha Lawson-Frost revisits the long-standing problem of "integrating" scientific evidence, as understood by the EBM movement, with patient values, clinical judgement and expertise, noting that "a significant amount of the literature on EBM" still "takes this integration to be unproblematic".[39] In line with our previous authors, Lawson-Frost notes that this issue is epistemic in nature, being "essentially the problem of how we can use information which is both general, (eg about a population sample), and descriptive, (eg about what expected outcomes are), to reach clinical judgements which are individualised (applying to a particular patient), and normative (about what is best for their health)." The author argues that the problem needs to be urgently addressed via "a more developed account of how clinicians can make inferences about what is best for their patients, based on the different kinds of information they have about evidence, values, and patient symptoms and histories."

As Ray Pawson observes, the lack of correspondence between tests of treatments and their application in real-world contexts is something "clinical research methodology has wrestled with" for over fifty years.[40] His paper discusses a proposed solution to this problem, "the pragmatic trial" - the proposal to conduct clinical trials in conditions corresponding more closely to everyday practice. The author states that this solution "has proved easier to utter than to execute", because the concept of the pragmatic trial is "essentially contested... there is widespread agreement on an idea but not on the best realisation". The paper concludes that, while there is clearly extensive support for the "pragmatic turn" in clinical research, there is profound disagreement on where that pathway will lead, and the precise role of shared decision-making and patient engagement in shaping practice is far from being determined.

The paper by Jon Williamson reminds us that even the integration of different conceptions of scientific methodology in clinical research is very far from being an issue resolved. Williamson praises the International Agency for Research on Cancer (IARC) for its use of a broader evidence base than is typically found elsewhere in biomedicine.[41] He identifies two evidential principles in the evaluation of carcinogenicity by the IARC: Evidential Proximity and Independence. Evidential Proximity is the principle that population-level studies on carcinogenicity carry more weight when they are closer to the population of interest; the principle of Independence notes that the carcinogenicity of each agent must be assessed independently of other agents. Williamson argues that these principles can lead to

inconsistencies and recommends a reformulation of both principles that more robustly considers mechanistic evidence.

Returning to the context of medical practice, Donald Stanley and Scott Sehon discuss medical reasoning and doctor-patient communication.[42] Taking as their starting point the need for clinicians to learn how to talk to patients "at all levels of education, from different cultures, patients bringing their own views on language use and comprehension", they argue that the pragmatist philosophy of Charles Pierce can be applied to help clinicians become more self-consciously aware, both of their own activities in diagnosing medical conditions and of the potential pitfalls of communication with patients. They illustrate their claims via a series of scenarios, showing how causal explanations and theory building are at work even in very simple verbal exchanges.

Berkeley Franz and John Murphy comment on the unmet need to account for the role of philosophy, beyond medical ethics, in planning, implementing and evaluating the delivery of health services based in, and responsive to, communities.[43] Such responsiveness requires attending to local knowledge and interpretations informed by the values and interests of community members. As persons at the centre of health care, these members are moral agents who need to be empowered to participate in guiding and controlling health care interventions in communities as intersubjectively constructed "life worlds". This need aligns with a philosophical shift away from the medical model of health care toward a biopsychosocial one that privileges patient and community perspectives.

In case we become too enthusiastic in our drive for inclusivity, Fran Pollner and colleagues remind us that not all parties with an interest in the outcomes of medical interventions should be part of the decision-making process.[44] The authors point out that medical device representatives often attend surgeries and build relationships with practitioners that can influence decisions in a way that is by no means transparent to all patients. As the dialogue of shared decision-making continues, this paper reminds us of the need for an ethical discourse on the nature of the market and the potential barriers to progress it presents.

Oliver Thomas discusses the ethics of clinical guidelines and the need for interpretation in their application.[45] Thomas considers the problems in finding a balance between an "over-zealous" conception of guidelines as "unbreakable rules" (which fails to recognise acceptable variation in practice) and an abandonment of all adherence to guidelines (which fails to recognise their utility in assisting practitioners and patients, all of whom are human beings and therefore fallible). Examining a number of applications with reference to moral theories, he argues that the process of writing and implementing guidelines is best understood through the lens of Virtue Ethics, which characterises the key role of guidelines as assisting practitioners in cultivating the right dispositions to promote sound judgement in context.

Marco Azevedo and Bianca Andrade analyse Darlei Dall'Agnol's account of "respectful care", arguing that "this single attitude... can represent an integrated form of moral practical knowledge in healthcare."[46] Contrasting his approach to alternative accounts of practical reasoning (including Toulmin's casuistry) they link the debate about ethics to broader epistemological questions, using the distinction between "knowing how" and "knowing that" (knowledge as action versus knowledge of propositions) to defend Dall'Agnol's theory of "practical cognitivism". In this respect, and despite their radically different starting points and methods, their paper resonates with the arguments of Hurst and Greenhalgh.[37] In each case, by abandoning the notion of knowledge as something "sitting in the mind", construing knowledge instead in dispositional terms – as a form of interaction – traditional distinctions between knowledge and decision-making, epistemology and ethics, are broken down. The result is a theoretical framework more directly focused on the needs of practice.[79]

This opening section concludes with two papers raising issues about our understanding of health, disease and science. Peter White discusses the difficulties in identifying the scientific causes of chronic fatigue syndrome(CFS), arguing that this may be "because the condition is hard to diagnose, difficult to classify, or because of its heterogeneous nature".[47] White is not denying or undermining the experiences of people diagnosed with CFS, but rather is questioning the utility of the classification in helping patients and practitioners address those difficulties. He suggests subdividing the condition into likely subgroups as a means of finding valid and reliable associations with potential causes. His concluding comments question our underlying philosophical assumptions about the nature of health and disease, including the

mental-physical illness dichotomy and the antithesis between organic and functional disease states.

Joseph Vere and Barry Gibson undercut the debate about integrating EBM's scientific knowledge with other forms of knowledge by arguing that, given both a plausible account of EBM and any defensible theory of science, EBM does not, in fact, meet the criteria to qualify as science: "any knowledge claims that are made through this approach do not deserve the status of science".[48] They do, however, add an important qualification: "This does not mean that evidence based medicine is not important or that the knowledge claims derived from this approach should not inform medical decision-making." If any defenders of EBM find this conclusion objectionable, then it may be appropriate for them to consider their own philosophical assumptions about the nature of knowledge and science in particular.[80] As the papers in the next section indicate, patient knowledge is not "scientific" but this does not mean it is somehow not "real" knowledge, or of a secondary nature to scientific knowledge, and its relevance to understanding proper decision-making in practice is beyond doubt.

Person-centred care and the phenomenology of illness

There is a growing recognition that patients' knowledge of their own experience is at once authoritative and indispensable, not only in understanding how to manage their condition, but also to get an adequate characterisation of what their condition really is.[13,81-85] This section contains three papers that explore patient experience in depth, explaining the importance of recognising the personhood of the patient. Without an appreciation of the context of a person's life, her goals and values, a description of symptoms can of course tell us something about the nature of "the problem", which may serve our purposes in some contexts, but which in other contexts can be unhelpful or even misleading.

In the first of two contributions to this edition, Derek Mitchell intertwines accounts of his own experience of illness, and the experiences of others which have been recounted to him, with discussion of some of the most influential philosophical work in human history, to develop a detailed and powerful account of what "the experience of falling ill tells us about the nature of our being".[49] The account of the relationship between the experience of serious illness and our awareness of our own mortality develops and applies insights from philosophers from Plato to Heidegger, and also the recent and important work in the phenomenology of illness contributed by authors such as Havi Carel. Heidegger's account of the experience of anxiety and the way that separates us from "the world of involvements" is a crucial starting point for the paper which follows, focusing on the journey "from person to patient and back again".[50]

Noting how easy it is for us to become depersonalised when we become patients, Mitchell argues (in line with contributors to previous editions of this journal[86,87]) that we can be compliant in this depersonalisation because "in the early stages, particularly of serious illness, we do not wish to face the fact that our body is failing". Rather than face this, "we separate ourselves from our illness": we do not take ourselves to the doctor for treatment, but rather we take our illness. Mitchell presents a compelling account of the "fragmentation" of the person that ensues, how health professionals and systems can push us in the direction of this depersonalisation, but also how we can regain the status of personhood while remaining users of the healthcare system. This account has implications for the best ways practitioners can develop relationships with patients that recognise their personhood, thus providing care that can meaningfully be characterised as "person-centred".

Karin Engebretsen discusses the continuing problems of people suffering from medically unexplained systems, who report "being epistemically marginalized or excluded by health professionals".[51] Engebretson adopts a phenomenological approach to understand "the human experience in this context-specific setting", using extensive evidence from interviews with participants who found the experience of encountering general practitioners to be akin to "taking part in a battle", and who reported feeling distrusted by others. This, the author notes, resulted in a "disconnection from their habitual lifeworld, which in turn triggered a shame reaction". This process had negative implications for recovery, and the paper concludes by noting the need to develop solutions to these problems, which address the "norms, values and attitudes" involved "as well as issues of power".

Shared Decision-Making

The section opens with a series of reports and papers presented to an international conference in March 2019. The conference, at the University of West London(UWL), UK, invited papers on 'Shared Decision-Making, Person-Centred Care & The Values Agenda' and was organised by UWL's European Institute for Person Centred Health and Social Care, in collaboration with the European Society for Person Centered Healthcare and the Collaborating Centre for Values-based Practice at St. Catherine's College, Oxford, UK. It included contributions from regulators and policy organisations – including the UK's National Institute for Health and Clinical Excellence (NICE) and Italy's National Research Council – as well as practitioners, patient experts and academics, on a broad range of issues confronting contemporary health services globally, as they attempt to give meaningful application to the core ideas identified in the conference title.

Following the conference address by Sir Andrew Dillon, chair of NICE, Clare Wohlgemuth and colleagues from NICE's Centre for Clinical Guidelines report on the organisation's efforts to establish a "shared understanding of shared decision-making in healthcare".[52] In their efforts to develop a guideline, NICE colleagues commence with a "scoping" process aimed at discovering the key challenges the guideline will need to address, thus "setting the parameters for what will be included in the guideline". Discussions with a range of stakeholders revealed divergent viewpoints, presenting difficulties in finding a common definition of Shard Decision-Making (SDM) and raising questions about "measurability, opportunities and barriers to implementation as well as feasibility". The report provides an interesting insight into how guideline developers go about attempting to respond to such challenges, in the case of a guideline that is still very much a work in progress.

Fiona Browne and colleagues from the General Osteopathic Council report on an inclusive process aimed at promoting person-centred care and SDM in osteopathic practice.[53] Discussions involving regulators, patients and practitioners attempted to identify patient and practitioner values, testing their application by using methods including case studies and considering barriers with reference to real patient narratives. The efforts to improve communication and mutual understanding include improving connections between different professionals, in an area where "practitioners work largely in sole-practice and without employers or teams". Like the work of Wohlgemuth and colleagues, this is very much a work in progress, and the authors detail the future stages of the project in their progress report.

A similarly complex and inclusive study is reported by Karin Drivenes and colleagues, investigating the relationship between practitioners' attitudes and the delivery of SDM in mental healthcare.[54] Tools to gather information from large numbers of practitioners were employed in conjunction with instruments to measure patients' experiences of SDM. The authors note that positive associations between practitioners' patient-centred attitudes and the successful implementation of SDM are clearly evidenced in the study, and they discuss the relevance of these findings for the accomplishment of SDM processes in mental health care.

Dilraj Kalsi and colleagues present a summary of "the current and potential use of SDM across a wide variety of specialties", noting the "nuanced and different challenges" to its implementation and development in the range of contexts they consider.[55] Examining SDM in primary care, mental health, paediatrics, palliative care and surgery, they note that, despite the important differences, there are sufficient similarities to make a meaningful evaluation of the progress SDM represents, as well as the resources needed to assure further progress in future. Their paper is followed by a brief commentary by Veryan Richards on the importance of communication in clinical practice and its relationship with therapeutic outcomes.[56] Drawing on her experience of training health educators, Richards discusses the use of language she characterises as 'person-first', inclusive, balanced and consistent. Her paper reminds us that communication is not an "add-on" to assist good practice but an integral part of it, shaping the nature of relationships and the therapeutic process.

The conference papers are followed by a important discussion of foundational questions about the nature of shared decision-making and what it means to be "person-centred". Mark Tonelli and Mark Sullivan consider a fairly straightforward model, given which SDM is primarily focused on treatment choices and represents a transaction between the clinician, who supplies scientific knowledge – thus providing the patient with treatment options – and

the patient, who contributes values and preferences and chooses on the basis of these.[57] This model is perhaps initially appealing because it implies that there is a fairly clear means of implementing SDM, but the authors argue convincingly that a more nuanced model is needed to give full regard to the autonomy of the patient and the personhood of the practitioner. To protect patients from paternalism, the simple model limits the practitioner to providing factual information and invites the patient to choose (based on her/his "subjective values") between the range of "evidence-based options" presented. But this fact/value distinction "represents a false dichotomy" which de-personalises the practitioner and paradoxically also "runs the risk of ignoring the very real facts, the experiential reality" of the patient's illness. The authors then outline a more meaningfully "shared" and person-centred approach to decision-making, with some similarities to the accounts of co-production referenced in our opening comments. They discuss the development of ongoing and respectful partnerships between clinicians and patients, that acknowledge the personhood of both parties and encourage an autonomy-supportive environment that is empathetic and mutually understanding.[57]

The paper by Jonathan Lewis provides a detailed account and critical analysis of standard accounts of SDM offered by some of its prominent proponents.[58] Lewis focuses in particular on the claim (made in numerous discussions of medical ethics) that SDM respects a patient's "relational autonomy" understood as "a capacity that depends upon, and can only be sustained by, interpersonal relationships as well as broader health care and social conditions." The paper describes two primary approaches to relational autonomy, arguing that standard accounts of SDM actually undermine patient autonomy when it is understood in this way. The paper concludes with an important challenge: if SDM is to respect patient autonomy, then its proponents need, as a matter of urgency, "to revise the requirements of SDM to ensure consistency with the standards of relational autonomy".

These important critical papers are followed by contributions describing and discussing numerous attempts and models to implement SDM and associated ideas in a range of practice contexts. Ann-Catrine Eldh's analysis of "patient participation" notes that stakeholders have "diverging understandings and expectations as to what patient participation is" and that "procedures for patient participation are not inevitably person-centred".[59] Eldh discusses a tool designed to facilitate greater mutual understanding of patient participation, but notes that "further studies are needed to operationalize patient preferences in clinical practice, in order to facilitate patient participation in healthcare". Chirk Jenn Ng and colleagues propose a dual-layered model of shared decision-making that helps to establish priorities for patients with complex multimorbities.[60] In each layer of the process, patients and primary care providers mutually decide on the focus of a clinical encounter and the ideal treatment. The model offers a clear and focused strategy when clinical resources are limited and consultations are short.

Min-Chun Chung and colleagues apply the Knowledge-Attitude-Behaviour model to probe perceptions of SDM in health care professionals working in various hospitals in southern Taiwan.[61] Their study revealed positive attitudes to SDM and predictable barriers to its implementation, identified as lack of time and knowledge and the difficulty of developing patient decision-aids: guides to shared decision making in specific contexts that can help clinicians work through a decision with their patients. The authors conclude that continuous emphasis on education regarding SDM can contribute to promoting a positive attitude to its acceptance and can influence the behaviour of practitioners. Farah Asa'ad evaluates the implementation of SDM in dentistry and the roles of patient decision-making aids(PDAs), concluding that "PDAs in various dental fields need to be further developed, in order to ensure a satisfactory integration of patients in the SDM process".[62] Arguing that dentistry is "behind" other areas of clinical practice in these respects, the author calls for educational interventions to help practising dentists and faculty responsible for educating dental students, to meet the precepts of SDM.

The paper is followed by a contribution from Georgette Eaton on the problem of "learning values".[63] The author notes that "professional values" are frequently identified as a "fundamental element" of SDM and that the British National Health Service has adopted a series of values that are seen as "foundational". Focusing specifically on the paramedic profession, Eaton notes there is very little research on how these values are actually learned and interpreted in practice. Her study involved paramedic students and educators submitting diary entries and taking part in focus groups, and highlighted the need for professional values

to be explored explicitly within the undergraduate curriculum, to enable paramedic students to understand and develop their values from an early stage.

Christopher Lamb and colleagues produced a path model of how physician decision-making style is associated with patient decision-making around treatment choice for primary immunodeficiency(PID), which is rare but expensive to treat.[64] The model was developed by applying structural equation analysis to cross-sectional findings from 330 web-based surveys completed by United States physicians treating over half the country's PID patients requiring immune globulin. These surveys had been completed by United States physicians treating over half the country's PID patients requiring treatment with immune globulin. The study compared the physicians with an affinity for using a slow, rational, analytical style of decision making around life-long treatment choices for PID, and those with a heuristic style that is fast and intuitive. A rational style was positively associated, both directly and mediated by a patient-centred approach, with patient participation with protocols. In contrast, a heuristic style was associated with increased participation with treatment tools.

Abhimanyu Ahuja highlights how heuristic biases can undermine the clinical encounter.[65] While heuristics are valuable shortcuts in clinical decision-making, they risk biasing physicians through stereotyping. Ahuja recommends a "deliberative model" of the physician-patient relationship that emphasizes communication and allows physicians to reflect more thoroughly on their biases. The acknowledgement and disclosure of such personal beliefs and biases on the part of practitioners is, according to Keith Begley and colleagues, a necessary condition of meaningful SDM.[66] The authors characterise such biases as "epistemic defeaters" to be overcome through a process of open dialogue. They share the results of a review of the interaction between SDM practices in maternity care and the frequency of and reasons behind recommendations for caesarean surgeries, drawing a link between attitudes toward women's knowledge and how important SDM was to practitioners.

The kernel of the authors' argument is that physicians owe pregnant and birthing women a duty of care that is specifically epistemic: a duty to acknowledge the special knowledge of these women, which is no less important than the physician's own knowledge in informing decision-making during maternity care. Physicians are also persons, who bring to the encounter values and external concerns that may influence their decision-making – hence the need to be transparent about their own "defeaters". In doing so, they act as equals, people who also have lives outside of the healthcare context, and legitimate concerns beyond the health of their patient. By giving the patient full knowledge in respect to their recommendations (not just the recommendation itself, but the reasons why they make it) practitioners move beyond "informed consent", and this transparency lays the groundwork for truly shared decision making, through which those defeaters might be overcome.

Some patients are reluctant to assert their care preferences to clinicians, especially in the face of critical illness. Karina Olling and colleagues report from Denmark their "before and after" study of the effect of a patient decision aid on SDM in this context.[67] Applying a validated tool, the OPTION scale, experienced oncology nurses independently observed decision support to facilitate patient-centred communication in real life. Regardless of clinicians' training in SDM, the decision aid produced a statistically significant overall increase in patients sharing preference-sensitive decisions about adjuvant therapy after breast cancer surgery, and especially in diagnostic work-up because of a small suspicion of lung cancer.

Eva Sather and colleagues employed a qualitative research design with a descriptive approach to reveal important factors in care pathways for former mental-health patients, in their transition between district psychiatric hospital centres and community mental health services in Norway.[68] They found that the importance of shared information between all parties was key to the provision of SDM in a way that actually helps patients seeking to develop the knowledge, skills and confidence to manage their own health.

In the paper by Marisa Sklar and colleagues,[69] we see a patient-centred approach being taken up at the institutional level, by Patient Centred Medical Homes(PCMH) – centres where a number of medical services can be found together within the same building, so that patients experience a whole body access to care, and medical services regularly interact and operate under a centralized administration. They studied the experiences of physicians and nurses who worked in this context and found that the more survey respondents experienced their own workplace as a site of shared responsibilities and collegial networks, the more they felt

the principles of the PCMH were truly put into place. The study indicated significant variability in PCMH characteristics across the United States and Canada. Sources of friction were perceptions that the workload of being patient-centered was not equally shared, or that interactions between other practitioners in their network were less than smooth.

Cristian Baicus and colleagues report their multi-centre, cross-sectional study of characteristics of SDM by outpatients around treatment for an autoimmune disease or atrial fibrillation in Romania.[70] Their study indicates that protecting the anonymity of patients increases the discriminatory power of their evaluation of the SMD process and should be part of the methodology of future evaluations of SDM, even at the cost of a reduced response rate. When completing the Romanian version of the 9-item SMD questionnaire validated in this study, the patients with an autoimmune disease rated the SMD process as lower when the rating was anonymously online rather than in the hospital. In contrast, it was low in both settings among those with lower education and either an autoimmune disease or atrial fibrillation.

Rahbel Rahman and colleagues report perceptions of patient-centered care among providers and patients in the orthopedic department of a tertiary care hospital in Karachi, Pakistan.[71] Their study examined the perspectives of 18 healthcare providers (nurses, consultant doctors, residents, radiologists, physiotherapists) and 18 patients regarding best practices for person-centred care and discovered significant agreements regarding the role of family in patient decisions, but some discrepancies regarding issues including the continuity of care offered post-discharge. The authors call for recurrent training to improve teamwork among providers, in particular "questioning the implicit agreement of patients who may be vulnerable to decision-making of authoritarian figures in their family". They also suggest including peer support workers or community health workers to offer aftercare support to patients in their home.

As cervical cancer screening is transitioning to include human papillomavirus (HPV) options, Canadian authors Brianne Wood and colleagues have responded to the need for a tool to elicit the preferences of women from among the available modalities for cervical cancer screening.[72] The Ottawa Decision Support Framework and International Patient Decision Aids Standards (IPDAS) quality criteria guided the design and feasibility testing of an online survey tool in a convenience sample of 25 highly educated women eligible for cervical screening. The test findings provided preliminary evidence that the tool can feasibly elicit informed, values-based preferences in a balanced manner among the available modalities. A refined tool could ultimately be used for research to inform screening guidelines or shared decision-making during clinical encounters.

Arguably some areas of practice provide far more serious challenges to implementing person-centred care and SDM than others. Camille Paynter and colleagues state that the methods of SDM include "eliciting and acknowledging patients' preferences for participation, patient choices regarding how decision-making processes will proceed, and respect and adherence of patient choices by their clinicians".[73] They note that decision-making becomes far more complex when there are "no curative treatment options" combined with "a high prevalence of communication difficulties and a lesser prevalence of cognitive difficulties within a context of a rapidly progressive condition", as seen in motor neurone disease.(MND) Their extensive review of the literature regarding decision-making within the MND population reveals that, while "most studies acknowledge that deficits in communication or cognition impact the decision-making process", current insights into the impact of communication and/or cognitive impairments on healthcare decision-making are extremely limited. Until this deficit is addressed, people with MND and their carers will not be adequately supported.

End-of-life decisions present another area where the meaningful application of person-centred approaches and SDM seems at once eminently important and particularly difficult to implement. Marion Douplat and colleagues conducted a prospective multi-centre study in three emergency departments of university hospitals in France, to describe the management of the decision-making process of withholding and withdrawing life-sustaining treatments.[74] The results made it clear that there is still very little anticipation in end-of-life decisions, and the authors conclude that "discussion with patients concerning their end-of-life wishes as well as the writing of advance directives, especially for patients with chronic diseases, must be encouraged early".

Inés Morán-Sánchez and colleagues focus on SDM in mental health and illness.[75] Their starting point is the observation that little is known about the extent to which people with severe mental illness actually want to be involved in the decision-making process. Their extensive study of outpatients with a range of mental disorders concluded that psychiatric patients "more frequently preferred a passive role in the decision-making process" and that interventions to promote SDM need to be carefully tailored to the values and needs of each patient, "because not everyone wants to participate to the same degree". While agreeing that "part of the SDM process entails allowing patients to not participate in SDM if that is their preference," and that "pressuring patients to engage in SDM undermines the goals of this model", Wilson Trusty and colleagues also site research supporting SDM for mental and behavioural health concerns, providing recommendations for increasing shared decision-making when working with patients.[76] The need to be person-centred, to tailor the approach to the specific needs and values of each patient, emerges from each article as an overriding concern if SDM is to be meaningful and actually helpful to clinicians and patients.

The section concludes with a paper by Kerstin Knight that focuses on an area where conceptual and practical problems are inseparable: the identity problem of advance care planning(ACP).[77] ACP is viewed as a form of shared decision-making between carers and patients who anticipate losing decision-making capacity, but such decisions raise serious and unresolved philosophical questions regarding the identity status of the mentally incapacitated person, and how to evaluate that person's rights and interests. Knight argues that a narrative account of identity best addresses the identity problem. Unfortunately, such an account seems incompatible with our current medico-legal framework for attributing decision making capacity. Thus, the law "espouses conflicting views as to who can be an appropriate decision making authority for patient care". Bodies governing medical care need to address these underlying questions as a matter of urgency, if they are to develop coherent policies and practices regarding SDM and person-centred care.

Book reviews

The edition includes three book reviews, including two offering different but complementary perspectives on the text: *Evaluating Evidence of Mechanisms in Medicine: Principles and Procedures*, by Veli-Pekka Parkkinen and colleagues. Lise Marie Andersen and Jesper Nørgaard Kjær regard this contribution as timely and valuable, given the on-going debate about evidence-based medicine and its relationship with mechanistic explanation.[88] While offering criticisms and suggestions for broadening the text's philosophical base, Adam La Caze agrees that the text addresses an important gap in the literature.[89]

Mary Walker reviews Thomas Schramme's *Just Enough Health: Theories of Health Justice*.[90] She recommends the text as a comprehensive introduction to the topic of health justice, and notes that the chapters on specific topics or the book as a whole would be an excellent resource for teaching introductory lessons or courses on this topic.

Concluding comments: SDM and person-centred practice

SDM and person-centred care offer exciting possibilities, but the process of giving these core ideas meaning and application is on-going and not without risk. Simplistic models, such as the one identified and effectively criticised by Tonelli and Sullivan,[57] are likely to seem more straightforward and appealing than the more nuanced models needed to deliver the progress many contributors to this volume clearly seek. The model of SDM as a transaction between practitioners as the providers of knowledge and the patient as a consumer of care is of course instantly intelligible to policy-makers and managers, resonating with the dominant market ideology of our era. [91] The dangers of regarding medical consumerism as the natural alternative to medical paternalism are also well recognised – see, for instance, Aquino's important work on "big-eye surgery"[92] which suggests that we do not succeed in treating patients as persons simply by asking them "of the options available, what do you want?", ignoring the broader cultural and economic context constraining their responses. As Pollner and colleagues note,[44] commercial interests will impact on the decision-making process in ways that do not always directly consider the broader interests and values of patients or indeed the ethics and values of practitioners. As Knight observes,[77] SDM is typically

understood as a process involving different kinds of agents who share the requirement to have "sufficient capacity for the decision in question". This understanding raises numerous conceptual and practical questions about how to enact this process when dealing with the many human beings whose decision-making capacity does not conform to standard models of "full capacity".

None of these difficulties should deter us from seeking the more nuanced, more challenging (both intellectually and practically) account of person-centred care and SDM defended by such authors as Tonelli and Sullivan,[57] and strongly suggested in the contributions of authors such as Hurst and Greenhalgh,[37] Azevedo and Andrade[46] and others. The important work of contributors to this edition gives us reason to feel assured that the serious work still needed to translate these important ideas into practice can indeed be done.

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