Linking Science with People: An Introduction to Part IV, Science

24

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That values-based practice links science with people is easily said, but as the chapters in this Part illustrate, it is often far from easy to put into practice. Here as elsewhere in the book, cultural values have a key role to play. Left implicit and unacknowledged, they may act as barriers to the process of linking science with people. Made explicit on the other hand, as part of a culturally enriched form of values-based practice, cultural values become powerful facilitators of the process.

24.1 Three Principles of Values-Based Practice Linking Science with People

The first four chapters in this Part between them explore the three principles of values-based practice defining its partnership with evidence-based practice in linking science with people. As described briefly in our introduction to values-based practice (chapter 1, “Surprised by Values: An Introduction to Values-based Practice and the Use of Personal Narratives in this Book”), and indicated in Table 24.1, the three principles are the Two Feet Principle, the Squeaky Wheel Principle, and the Science Driven Principle.

The editors with input from the contributors to Part IV.

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<ul style="list-style-type: none">• Chapter 32, “Discovering Myself, a Journey of Rediscovery”—Waldo Roeg

24.1.1 The Two Feet Principle

The *Two Feet Principle* states that *all decisions are based on the two feet of values and evidence, including decisions about diagnosis.*

It has become a truism in contemporary health care that clinical decisions should be evidence based. The *Two Feet Principle* reminds us that clinical decisions should be values-based as well. This values-plus-evidence approach is the basis of the shared decision-making underpinning contemporary person-centered clinical care.

Chapter 25, “A Cross-Cultural Values-Based Approach to the Diagnosis and Treatment of Dissociative (Conversion) Disorders,” by Bulgarian psychiatrists, Anna Todeva and Assen Beshkov of the Medical University of Plovdiv, illustrates the clinical importance of the Two Feet Principle applying to decisions about diagnosis as well as treatment. The story they describe is of A.A., a woman of Roma origin, who presents with recurrent dissociative symptoms (bodily symptoms due to psychological causes). She eventually responds to evidence-based interventions but only when these are used with due regard to the cultural and other values impacting on her presenting symptoms.

A.A.’s story in chapter 25, can helpfully be read in conjunction with that of Ms. Suzuki in the next chapter, chapter 26, “Treatment of Social Anxiety Disorder or

Neuroenhancement of Socially Accepted Modesty? The Case of Ms. Suzuki” (see below), in that both focus on the role of values specifically in diagnostic assessment (broadly conceived as how a problem is understood) as distinct from treatment (broadly conceived as how a problem is dealt with). This twin dependence of diagnostic assessment, on values as well as on evidence, is important in all areas of health care—recall the story from surgical care of Mrs. Jones’ Knee in chapter 1, “Surprised by Values: An Introduction to Values-Based Practice and the Use of Personal Narratives in this Book.” That this twin dependence is no less (and may be more) important in psychiatry even than in surgery is well demonstrated by the stories in chapters 25, “A Cross-Cultural Values-Based Approach to the Diagnosis and Treatment of Dissociative (Conversion) Disorders” and 26, “Treatment of Social Anxiety Disorder or Neuroenhancement of Socially Accepted Modesty? The Case of Ms. Suzuki.” We return to this point below (see Sect. 4, Values in Psychiatric Diagnosis).

24.1.2 The Squeaky Wheel Principle

The *Squeaky Wheel Principle* states that *we notice values when they cause difficulties (like the squeaky wheel) but (like the wheel that doesn’t squeak) they are always there and operative. The principle has counterpart implications for evidence.*

Chapters 26, “Treatment of Social Anxiety Disorder or Neuroenhancement of Socially Accepted Modesty? The Case of Ms. Suzuki” and 27, “Nontraditional Religion, Hyper-religiosity, and Psychopathology: The Story of Ivan from Bulgaria” in this Part exemplify the two sides of the Squeaky Wheel Principle: chapter 26 is concerned with its implications for values, and chapter 27 is concerned with its counterpart implications for evidence. In chapter 26, Eisuke Sakakibara, a neuropsychiatrist at the University Hospital in Tokyo, recounts the story of Ms. Suzuki, a Japanese woman in her middle years, who is referred to a psychiatrist for treatment of social anxiety. This raises troubling ethical questions for the psychiatrist: is this merely neuroenhancement or legitimate treatment of a genuine disorder? Here then, consistent with the Squeaky Wheel Principle, our attention is drawn to the cultural and other values in play because they are conflicting (notably the ethical values in this instance) are ‘squeaking.’

The next chapter, chapter 27, “Nontraditional Religion, Hyper-religiosity, and Psychopathology: The Story of Ivan from Bulgaria,” by Ivo Mitrev and Mladen Mantarkov from the Medical University of Plovdiv in Bulgaria, provides yet a further illustration of the importance of values in psychiatric diagnosis, this time through the prism of the counterpart implications of the Squeaky Wheel principle, i.e., for evidence. Like chapter 26, chapter 27 exemplifies the Squeaky Wheel principle. But where chapter 26 exemplified the Squeaky Wheel principle as applied to values, chapter 27 exemplifies the principle as applied to evidence. Chapter 26 says

‘when the values are visible (‘squeaking’) don’t forget about the evidence.’ Chapter 27 says ‘when the evidence is visible (‘squeaking’) don’t forget about the values.’

Ivan, the subject of Mitrev and Mantarkov’s case narrative, converts to Orthodox Judaism as a young man. This is so unusual in his native culture that he ends up being treated in a psychiatric institution. Once there, however, differences of opinion emerge about whether there is anything psychiatrically wrong with him. Resolving these differences is where values come into play diagnostically. The issues in this instance turn on how the DSM’s ‘criteria of clinical significance’ are interpreted and applied diagnostically. Key to this, as Mitrev and Mantarkov show through Ivan’s story, is a series of cultural and other values.

This is how the argument goes. For an experience or behavior to be ‘clinically significant’ in DSM’s terms, it must be associated with dysfunction in one or more social areas such as ‘work, interpersonal relations or self-care.’² But what counts as *dysfunction* in these areas varies from one culture to another according to the values of the culture concerned. Hence, consistent with the Two Feet Principle of values-based practice and notwithstanding the DSM’s claim to be a descriptive (hence value free) diagnostic classification (see Footnote 1), this crucial aspect of the differential diagnosis between hyper-religiosity and psychopathology turns critically on balancing a series of contested values. If therefore even the (supposedly) descriptive DSM requires in its application to diagnostic assessment, a process of balancing contested values, it seems likely that something of the same balancing of values will be required across psychiatric diagnosis as a whole.

24.1.3 The Science Driven Principle

The *Science Driven Principle* asserts that *advances in medical science drive the need for VBP (as well as EBP) because they open up choices and with choices go values*

The Science Driven principle takes the links between values and evidence in the delivery of health care to a whole new level. Where the Two Feet and Squeaky Wheel principles emphasize different aspects of the twin requirement for both

¹The DSM is the American Psychiatric Association’s Diagnostic and Statistical Manual [1]. Adopted in many countries as the ‘bible’ of scientific psychiatry, its aim is to place psychiatric diagnosis on a firmly evidence-based footing. For more on the DSM and values, see the Guide to Further information at the end of this chapter.

²DSM’s ‘criteria of clinical significance’, as they are called, all take broadly the same form. For schizophrenia, the required criterion is ‘Criterion B’. With value words italicized, this reads: ‘For a significant portion of the time since the onset of the disturbance, level of functioning in one or more major areas, such as work, interpersonal relations, or self-care, is markedly *below* the level achieved prior to the onset (or when the onset is in childhood or adolescence, there is *failure* to achieve expected level of interpersonal, academic, or occupational functioning’ [1, p 99].

values and evidence in health care, the Science Driven principle identifies the origins of this twin requirement in the very progress of medical science.

Thus, it is well recognized that advances in medical science drive the need for evidence-based practice: without the meta-analyses and other resources of evidence-based practice, we are simply unable to keep up with the rate of these advances. Less well recognized though is that the same advances are driving the need also for values-based practice: this, the Science Driven Principle reminds us, is because the impact of these advances in clinical practice is to widen the choices available to patients and with choices go values.

The Science Driven principle, it is important to emphasize, applies across the board in medicine—it applies in surgery no less than in psychiatry. But that the principle is of particular importance in psychiatry is well illustrated by David Crepaz-Keay, Jehannine Austin, and Lauren Weeks in chapter 28, “Journey into Genes: Cultural Values and the (Near) Future of Genetic Counselling in Mental Health” with their science fiction ‘Journey into Genes’. The story in this chapter is set in the near future and examines through a fictional genetic psychiatric counseling session, with ‘Jim Smith’, the way advances in psychiatric genetics already in the scientific pipeline are likely to impact practice. In Jim Smith’s story, advances in genetics do indeed offer answers to some of the questions that currently come up in genetic counseling. But on closer inspection, we find that consistent with the Science Driven Principle, such answers as are provided by these advances come at the cost of a whole series of further questions arising from the new choices for patients that come with them.

The authors of this chapter are uniquely well placed between them to understand the impact on practice of advances in psychiatric genetics. The lead author, David Crepaz-Keay, besides being Head of Empowerment at the Mental Health Foundation, is a member of the Ethics Committee of the International Society of Psychiatric Genetics. The committee’s remit includes considering the implications for mental health stakeholders of current advances in genetics. Jehannine Austin, the second author, is a professional geneticist and genetic counselor. Like David, she is a member of the Ethics Committee of the International Society of Psychiatric Genetics. David and third author, Lauren Weeks, are collaborating on a pilot program for the Mental Health Foundation exploring the perspectives of mental health service users on genetic advances.³

24.2 The Values Tool Kit

The next three chapters illustrate some of the resources for linking science with people available from what we called, in chapter 1, “Surprised by Values: An Introduction to Values-Based Practice and the Use of Personal Narratives in this Book,” the ‘values tool kit’. These resources are represented here by African philosophy, by transcultural ethics, and by anthropology, respectively. This selection of

³For more on this study, see the Guide to Further Information at the end of chapter 28, “Journey into Genes: Cultural Values and the (Near) Future of Genetic Counselling in Mental Health.”

‘values tools’ is of course far from exhaustive. But we hope that it serves to indicate the now very wide range of resources available for working with cultural and other values in mental health.

First, then, with Samuel Ujewe’s and Werdie van Staden’s chapter 29, “Policy-Making Indabas to Prevent “Not Listening”: An Added Recommendation from the Life Esidimeni Tragedy,” on the administrative indaba, we return to a theme highlighted in earlier Parts, the resources offered by African thought and practice for health care. Complementing van Staden’s chapter 21, ““Thinking Too much”: A Clash of Legitimate Values in Clinical Practice Calls for an Indaba Guided by African Values-Based Practice,” on the ‘clinical indaba,’ this chapter illustrates through a real (and widely publicized) story, the tragic consequences that followed from a failure of health service managers adequately to engage in an ‘administrative indaba’ involving not just the service users who were the recipients of their decisions but also their families and the communities from which they came. Ujewe and van Staden show how deep this failure ran. It was particularly acute in an African context in which one’s very identity is inextricably woven together with one’s social context. But there is surely a wider message here about the importance of genuine consultation for the administration of mental health services in any part of the world and about the ‘administrative indaba’ as a model for implementation.

The importance of ethics in the values tool kit is well illustrated in chapter 30, “Covert Treatment in a Cross-Cultural Setting” by Neil Pickering’s nuanced account of the interaction between values-based practice and transcultural ethics in the context of covert (or involuntary) treatment. Combining these two approaches as in Neil’s chapter provides a balanced approach that avoids abusive uses of psychiatry developing across very different (and to an extent conflicting) sets of cultural values. Chapter 31, “Discouragement Towards Seeking Health Care of Older People in Rural China: The Influence of Culture and Structural Constraints” continues the challenge of balancing differences of values, this time between generations, with Xiang Zou’s anthropological study of elderly health seeking behavior in rural China. Xiang’s work provides a powerful illustration of the role of anthropological and other empirical social science methods in promoting cross-cultural understanding of the otherwise hidden cultural values impacting on health care.

24.3 StAR Values and Recovery

It is natural that in health care, the focus should be on negative values. The very point of health care, after all, is to deal with health *problems*. But the crucial importance of focusing also on the positives, on what are called in values-based practice ‘StAR values’ (Strengths, Aspirations, and Resources), is well illustrated by the final chapter in this Part, Waldo Roeg’s autobiographical chapter 32, “Discovering Myself, a Journey of Rediscovery.” As Waldo’s story graphically illustrates, the problems he has faced as a mental health service user have been all too evident. But recovery, the processes involved in dealing with these problems effectively, required, as Waldo puts it, genuinely recognizing “... the strengths and contribution that everyone can make.”

The importance of focusing on strengths as well as problems in mental health assessment became clear in a program on values-based practice supported by the UK's Department of Health in the early years of this century. Called the 'The 3 Keys programme' [2, 3], one of the eponymous three keys to mental health assessment was that it should be strengths-based.⁴ It was from this program that the StAR values of values-based practice were later developed. The importance of the StAR values for recovery runs through Waldo's story and the inspiring work of the Recovery College movement of which he is now a part. The 3 Keys programme is also being taken forward through the Bristol Co-production Group to which the authors of the dialogue in chapter 23, "Recovery and Cultural Values: On Our Own Terms (A Dialogue)," Justine and Rick, both belong. Waldo, Justine, and Rick recently collaborated on a short film bringing together their experience of the realities of coproduction (there is a link to this in the Guide to Further Information at the end of chapter 32, "Discovering Myself, a Journey of Rediscovery").

24.4 Values in Diagnostic Assessment

We make no apology for the emphasis on diagnostic values in this Part. Diagnosis is regarded by many of those committed to what they take to be an exclusively scientific view of medicine, as being value free. Decisions about treatment, this view acknowledges, may indeed bring values together with evidence. But diagnostic assessment, the processes involved in coming to an understanding of a problem as distinct from decisions about how that problem should be treated, is, so this view insists, a matter of fact to be decided by value-free science.

To do justice to this value-free view of diagnosis would take us into the long-running debate about whether health concepts (disease, illness, dysfunction, and the like) are, or may be redefined to be, value-free. Values-based practice, as has repeatedly been said, is committed to a scientific view of medicine. The theory guiding values-based practice suggests however a rather different understanding of what exactly is entailed by a *scientific view of medicine*. It suggests that, whatever may or may not be the merits of a value-free view of the nature of science (see below, Sect. 5), when it comes to linking science with people in the context of clinical decision-making (including decisions about diagnosis), values inevitably come into play.

We saw values coming into play clinically in the last Part in relation to the shared decision-making of contemporary person-centered practice. We see them coming together again, here in this Part, in the various principles linking values with evidence (chapters 25, "A Cross-Cultural Values-Based Approach to the Diagnosis and Treatment of Dissociative (Conversion) Disorders," 26, "Treatment of Social Anxiety Disorder or Neuroenhancement of Socially Accepted Modesty? The Case of Ms. Suzuki," 27, "Nontraditional Religion, Hyper-religiosity, and Psychopathology: The Story of Ivan from Bulgaria,"

⁴The other two keys, consistent with the program's focus on values-based practice, were that assessment should be person-centered and multidisciplinary. For more on the program, please see the Guide to Further Information at the end of the Chapter.

and 28, “Journey into Genes: Cultural Values and the (Near) Future of Genetic Counselling in Mental Health”), in the resources of the values tool kit (chapters 29, “Policy-Making Indabas to Prevent “Not Listening”: An Added Recommendation from the Life Esidimeni Tragedy,” 30, “Covert Treatment in a Cross-Cultural Setting,” and 31, “Discouragement Towards Seeking Health Care of Older People in Rural China: The Influence of Culture and Structural Constraints”), and, above all, in the importance of looking at strengths (StAR values) as well as problems in any approach to diagnostic assessment that is pertinent to the demands of recovery practice (chapter 32, “Discovering Myself, a Journey of Rediscovery”).

24.4.1 Three Ways of Understanding Diagnostic Values in Mental Health

Diagnostic values, although discernable in other areas of health care,⁵ are particularly strongly evident in mental health. It is only in mental health, for example, that values are explicitly expressed in its diagnostic manuals (see [5], for a detailed linguistic analysis of the extent and variety of values evident in the American Psychiatric Association’s DSM, [1]).

The prominence of diagnostic values in psychiatry has been variously understood. Some have taken this to show that mental health is a scientifically underdeveloped area of medicine (for an early and authoritative statement of this view, see [6]); others that mental illness itself is a myth [7]. The theory underpinning values-based practice suggests instead a third and very different interpretation [8]. This draws on work on the language of values by the Oxford philosopher, RM Hare [9]. Summed up aphoristically this Hare-inspired interpretation is that ‘*visible values = diverse values*’. In other words, the visibility of diagnostic values in mental health reflects the *relative diversity of the individual values* involved in the areas of human experience and behavior (such as emotion, desire, volition, belief, sexuality, and so forth) with which mental health is concerned.

Thus, in bodily medicine, the values involved are generally shared between clinician and patient. In Mrs Jones’ story (chapter 1, “Surprised by Values: An Introduction to Values-Based Practice and the Use of Personal Narratives in this Book”), for instance, the operative values (pain and mobility) were shared between her and the surgeon, Mr Patel. In mental health, on the other hand, as the stories throughout this book so richly illustrate, the corresponding values, involving as they do areas such as emotion, desire, volition, belief, sexuality, and so forth, are highly diverse. Our values in these areas vary not only between clinician and patient but also from one person to the next. Small wonder then that if ‘visible values = diverse values’ the values involved in psychiatric diagnostic assessment should be more visible than their counterparts in bodily medicine.

⁵ See for example the story of Mrs Jones’ Knee in chapter 1, “Surprised by Values: An Introduction to Values-Based Practice and the Use of Personal Narratives in this Book”; for another example, see [4].

24.4.2 ‘Visible Values = Diverse Values’ and the Three Principles

This Hare-inspired third way of understanding diagnostic values runs through and illuminates the three principles of values-based practice linking science with people. First, it is directly reflected in the Two Feet Principle—the ‘two feet’ of values and evidence underpin *all* decisions this principle states, including decisions about diagnosis. Then, second, ‘visible values = diverse values’ is itself an instance of the Squeaky Wheel Principle—the visibility of values in diagnostic assessment in mental health is an instance of the diverse values in question coming to our attention or, in the terms of the principle, ‘squeaking’.

Third, ‘visible values = diverse values’ is reflected (this time in anticipation) in the Science Driven Principle. Diagnostic values that is to say may for now be relatively invisible (because relatively homogeneous) in bodily medicine; but with the new choices opened up by advances in medical science and technology, the Science Driven Principle suggests that diagnostic values may well become as visible in bodily medicine (because they will become as diverse) as they are already in mental health. Infertility treatment is one such area where this has already happened [10]. That mental health is not immune to the effect of such advances is well shown by chapter 28, “Journey into Genes: Cultural Values and the (Near) Future of Genetic Counselling in Mental Health” in this Part—David Crepaz-Keay and colleagues’ science-fiction journey into the near future of psychiatric genetics illustrates how advances in medical science and technology by opening up new choices, far from driving values out of mental health, actually drive them even further in.

The ‘visible values = diverse values’ interpretation, it is worth adding finally, has a particular resonance in mental health, in part negatively, as a foil against abusive practices (as shown notably by Ivan’s story in chapter 27, “Nontraditional Religion, Hyper-religiosity, and Psychopathology: The Story of Ivan from Bulgaria,” this Part) and, in part positively, as a resource for recovery (as shown notably by Waldo’s story in the closing chapter of this Part, chapter 32, “Discovering Myself, a Journey of Rediscovery”). Like other areas of values-based practice, the importance of diagnostic values in both these respects (negative and positive) has in the past been understood largely in terms of individual values [8]. The contributions to this Part extend our understanding of the importance of diagnostic values in mental health to include cultural values as well.

24.5 Conclusions

We have outlined how the contributions to this Part explore some of the ways in which cultural values support an enriched model of the role of values-based practice in linking science with people. Cultural values enrich understanding of the three principles of values-based practice that together spell out key aspects of the relationship between values and evidence in health care, the Two Feet principle (chapter 25, “A Cross-Cultural Values-Based Approach to the Diagnosis and Treatment of Dissociative (Conversion) Disorders”), the Squeaky Wheel

Principle (chapters 26, “Treatment of Social Anxiety Disorder or Neuroenhancement of Socially Accepted Modesty? The Case of Ms. Suzuki” and 27, “Nontraditional Religion, Hyper-religiosity, and Psychopathology: The Story of Ivan from Bulgaria”), and the Science Driven principle (chapter 28, “Journey into Genes: Cultural Values and the (Near) Future of Genetic Counselling in Mental Health”); cultural values also enrich understanding of other tools in medicine’s values tool kit, illustrated here with the ‘administrative indaba’ of African philosophy (chapter 29, “Policy-Making Indabas to Prevent “Not Listening”: An Added Recommendation from the Life Esidimeni Tragedy”), transcultural ethics (chapter 30, “Covert Treatment in a Cross-Cultural Setting”), and anthropology (chapter 31, “Discouragement Towards Seeking Health Care of Older People in Rural China: The Influence of Culture and Structural Constraints”); and cultural values come at the heart of the strengths and other values supporting recovery (chapter 32, “Discovering Myself, a Journey of Rediscovery”). We explored the importance of cultural values particularly in diagnostic assessment in mental health.

24.5.1 Cultural Values and Scientific Research

In this Part, we have followed established convention in focusing on the role of values-based practice in linking science with people specifically in the clinical encounter. But the clinical encounter, as Steve Gillard indicates in his contribution to chapter 46, “Beyond the Color Bar: sharing narratives in order to promote a clearer understanding of mental health issues across cultural and racial boundaries”, is only the last in a long chain of connections between science and people. The links in this chain include the selection of research priorities and the administration of research funding, several aspects of the planning and execution of research (including the identification of ‘variables of interest’, the recruitment of research subjects, and the analysis and interpretation of data), peer review and publication, the development of evidence-based guidelines, and the gateway processes of regulation.

Cultural and other values play crucial if largely unacknowledged roles in each and every one of the links in this chain. Only by making these values explicit, as the contributions to this Part make them explicit in clinical decision-making, will we truly be in a position to link science effectively with people in mental health or indeed in any other area of health care.

24.6 Guide to Further Information

For a comprehensive analysis of the pervasiveness and diversity of values in the DSM (the American Psychiatric Association’s *Diagnostic and Statistical Manual*), see John Sadler’s book on ‘Values and Psychiatric Diagnosis’ [5].

For further reading on all aspects of diagnostic values, please see the Reading Guide and other sources available on the website for the Collaborating Centre for Values-based Practice in Oxford at: valuesbasedpractice.org/More about VBP.

This part of the website includes a free-to-download full text PDF of the ‘3 Keys’ publication [2].

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