Beyond dichotomies: confronting the complexity of how and why individuals come or do not come to mental health care

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With up to 50% of individuals in the “developed” world and up to 85% in the “developing” world assessed to have mental health problems but receiving no treatment (1), inevitable questions arise about the reasons for the gap. There are standard explanations – issues of access, cost and manpower; issues of mental health literacy or lack thereof; and of course, the large set of issues of prejudice and discrimination that we call stigma. But the now extensive list of research correlates that have been documented across hundreds of studies have yet to unravel the subtleties that underlie the dilemma of unmet need.

Here, a slightly different approach takes some liberties with classic and cutting-edge findings to set a foundation for a holistic, cross-cultural understanding of how person-related and service-related factors come together to influence how individuals respond to the onset of mental health problems. These general principles are writ large, embracing the notion that people, places and professions matter in all times and in all places, even as they play out differently in different societies.

SERVICE UTILIZATION RESEARCH: A BRIEF ORIENTATION

At least since the middle of the last century, utilization theories from diverse disciplines developed, placing primacy on different explanations of entry into treatment. Somewhat crudely put, medicine and psychiatry look to etiologically-based practices and professionals; anthropologists and psychologists look to cultural beliefs and individual motivations respectively; and economists and sociologists look to fiscal availability and organizational arrangements of services, including larger structures of inequality that facilitate or hinder access.

Over time, disciplinary perspectives have taken each other into account, resulting in a proliferation of revised models, hybrid models, and a nearly endless stream of diagrams or frames that purport to be new theoretical models. Yet, we still do not have a simple and clear answer about unmet need. Perhaps the dichotomous conceptualizations we tend to use in both research and practice stand in the way: either people see a physician or they don't; either people see a psychiatrist or a general practitioner; either it is their beliefs or their lack of insurance that matters; or either

people belong to a majority group and think this way or they are part of an ethnic/racial/geographic minority and they do not. The list of paired comparisons is lengthy.

What is clear is that the messy realities of confronting the onset of mental health problems in every society challenge traditional ways of thinking. Perhaps *each* major approach brings a unique wisdom to the understanding of how individuals get, or fail to get, to services. If we are to understand the factors or forces, from local to global, that affect whether individuals with mental health problems end up receiving care, perhaps only a mosaic of the empirically validated, central points of each perspective can fully represent the complexity of the public response to the onset of mental illness (2).

FINDING 1: MULTIPLE PATHWAYS TO CARE EXIST IN EVERY SOCIETY ARISING, AT LEAST IN PART, FROM INDIVIDUALS' ATTEMPT TO USE THEIR OWN “COMMON SENSE” VISION (3)

Even individuals who end up in the same mental health treatment center are likely to have traveled very different pathways to get there. There are different, but regular and routine, pathways to care, molded to time and place. In the US, for example, just under half of those who had their first major contact with the public mental health system made any kind of decision to do so. Over a quarter ended up in the mental health system through a coercive pathway, whether brought in by social control authorities (e.g., police, jail/prison system, judicial discretion) or seriously pressured by their families. Even more curiously, over a third of individuals reported they “muddled through”, traveling a pathway that was neither one they designed nor was designed for them against their will (4).

All societies hold a reservoir of different kinds of lay and professional “advisors” that are likely to have been involved in the pathway to care. These “gateway providers” (5) determine crucial trajectories that shape outcomes. While we may be comforted by the finding that those who have the most serious mental health problems almost always get to treatment, this should be offset by the early and recent research which reveals that pathways, even for the most severe cases, tend to be lengthy in terms of time and numerous in terms of options sought (6-8).

ARG – Argentina; BEL – Belgium; BGD – Bangladesh; BGR – Bulgaria; BRA – Brazil; CYP – Cyprus; DEU – Germany; ESP – Spain; GBR – Great Britain; HUN – Hungary; ISL – Iceland; KOR – Korea; NZL – New Zealand; PHL – Philippines; USA – United States; ZAF – South Africa

Figure 1 The relationship between suggesting psychiatrist for schizophrenia and number of psychiatrists ($r = .03$, ns) (adapted from 13)

Thus, the implication of these findings is that not all utilization is “help-seeking”, at least not necessarily by the individual affected; and, pathways are not efficient, even for the most serious cases. Thinking of service use under typical assumptions only interferes with our ability to understand the realities of responding to onset and the challenges of unmet need. The basic meaning of the response onset for individuals may be best captured by Anderson et al’s “containment” (9), that is, the interpretation of changes in body and mind reflects social and cultural circumstances and experiences that tend to normalize the situation and respond with minimal changes in routines.

FINDING 2: THE USE OF SERVICES IS NOT A SOLITARY PROCESS NOR AN IDEOLOGICALLY-FOCUSED JOURNEY TO FORMAL TREATMENT

This is, of course, in some ways a corollary of the first set of findings. Yet, implicit in many theories of health services use is the image of a decision-maker, a rational individual weighing the costs and benefits of seeking care. Some approaches add in the influence of those around them (e.g., as “norms”) as one more contingency in the calculus. Yet this view clashes with a now substantial body of research that onset, recognition and response are embedded in social networks. Illness behaviors are not just what individuals “do” (visit a clinic, pray, take over-the-counter medications, self-medicate with drugs and alcohol, exercise) but include those “individual consultations”, sometimes wanted, sometimes forced (e.g., employers, teachers, parents), that are activating forces.

Social influence plays a big part of what happens in unmet need, by suggestion or substitution. Throwing out or clinging to the idea of “agency”, that every instance of illness behavior is planned, thought out, and decided, is naïve. Individuals are neither lone, individualistic actors nor are they puppets of others or of the place and times in which they live. As described above, individuals may be proactive, they may go along, or they may resist. And, they may change their stance along the way. But they are always accompanied by what Antonucci (10) calls their “social convoy”. Whether their social ties to others are extensive or decimated matters, and whether their networks hold informational and emotional resources or not shape use.

FINDING 3: CULTURE MATTERS AT THE INDIVIDUAL, THE LOCAL AND THE NATIONAL LEVELS

Again, these findings link and build on each other. If the structure of social networks matter, their counterpart in molding pathways is culture. Local ideas, beliefs, meanings and attitudes are embedded in and transmitted through the set of human ties in everyday life. As Mojtabai (11) recently demonstrated, even the larger, national context of stigma is associated with whether individuals support treatment use or not.

Culture also impacts treatment directly. Provider beliefs about what their patients *believe* turns out to be a poor substitute for specific knowledge that can be gained in the interaction itself. Individuals do not have to ideologically align themselves with one or another tradition of healing, one or another way of thinking about the etiology of mental illness. While providers may hold an ideological stand inculcated through professional training or apprenticeship, individuals do not. They can simultaneously hold beliefs about genetic causation and about “god’s will” as part of the underlying etiology. These layers of beliefs allow for a practical and flexible response which translates into pathways to care when problems are not resolved. Culture may determine where that pathway starts, an individual’s “cultural toolbox” may shape next steps, but whether relief is found will determine the pathway’s endpoint.

FINDING 4: A SOCIETY’S ORGANIZATIONAL ARRANGEMENTS FOR CARE SET THE LIMITS AND THE POSSIBILITIES OF PATHWAYS TO CARE

Andersen (12), pioneering the role of access, famously noted that even individuals who hold the right beliefs and have great need can only use services if those can be acted upon because of geographical and financial availability. But again, findings do not line up with simple expectation. Figure 1 shows data from 15 countries in our Stigma in Global Context Study (13), a theoretically

and methodologically-synced, nationally representative study of public understanding and response to mental illness. When asked the open-ended question, “What should [name] do, if anything?”, immediately after being read a case scenario of a person meeting DSM/ICD criteria for schizophrenia, there is little correspondence between availability of psychiatrists and the spontaneous mention of this option. Individuals in some countries with a moderate number of psychiatrists per capita (e.g., Great Britain) do not mention psychiatry, while many who have little hope of ever seeing a psychiatrist (e.g., Bangladesh) do. Of course, these findings are curious and bear more analysis and interpretation than possible here. The point here is, again, to show that what we “know” and what “we think we know” can be two different things, requiring us to recast our ideas given the wealth of data and a new era of science.

CONCLUSIONS

Mental illness lies in the area of complex diseases. How the public understands and reacts, and how that is linked to their illness behavior, represents a complex response. In the end, the public only seeks to be better – better than before the severe symptoms of many mental health problems diminished their well-being and, for many, created a critical turning point in their life trajectory. If, like other areas of science, we are poised at a new era of understanding which demands that our research embrace delays, missteps and pathways, our models and findings may provide a more useful foundation for improvements in clinical and community practices. If we assume complexity – that large interacting systems shape what people, including providers, do – we will synthesize rather than separate; ask rather than assume; and conceptualize messy reality rather than strive for false parsimony.

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