What’s in a Name? Let’s Keep Asking

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The names we call each other stir passions, as we see from two recent commentaries on naming in psychiatry. Pamela Hyde, Director of the Substance Abuse and Mental Health Services Agency, urges us to use terms that recognize the many individualized paths to recovery people with mental illnesses follow. Fuller Torrey urges us to call people with schizophrenia “patients.” This commentary suggests that, by respecting the preferences of those being named, clinicians may enhance engagement in treatment and demonstrate respect for people as individuals beyond the label of a disease.

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Fuller Torrey’s commentary1 is in response to a request for dialog recently made by Pamela Hyde, the Administrator of the Substance Abuse and Mental Health Services Administration (SAMHSA), concerning terms that are used, or avoided, within the mental health community.2 Reading only Torrey’s commentary, a reader would mistakenly be led to believe that the call from SAMHSA focused on people with schizophrenia. Because Hyde was reflecting on the use of language to designate a broad range of people who receive care and services from mental health professionals (a future study might be done on what we like, and don’t like, to call ourselves), Torrey’s focus on schizophrenia alerts the reader to his narrower perspective on this multifaceted issue.

Torrey begins by stating, “In deciding what words to use, a logical starting point is to ask what schizophrenia is.” But one could similarly argue, “In deciding what words to use, a logical starting point is to ask a person what he or she wants to be called.” Hyde, unlike Torrey, indicates that any term we use to describe the people who are intended to benefit from our services might be problematic to someone for some reason. At the heart of her commentary is the recognition that who the speaker is and to whom he or she is speaking matters a great deal in determining whether any particular term is acceptable. The notion of respecting the preferences of the person who has schizophrenia is virtually absent from Torrey’s reply. Such respect is important for more than reasons of human decency (although that would be enough). The number of 1-session episodes of care in many mental health clinics is another, suggesting that we need to do a much better job of engaging people in treatment.

Based on his conclusion that schizophrenia is a clearly identifiable biologically based illness, Torrey sees no reason to shy away from naming his targets as “people with schizophrenia” and naming those who have received treatment as “patients.” He dismisses all those who would disagree with him as misguided. Anyone who makes a social or cultural critique of the practices of naming and making deviant the symptoms of persons identified as having schizophrenia is tossed into the “mélange” of theorists and activists who are relics of the 1970’s or simply uninformed of the evidence he marshals regarding the “abnormalities of structure and function” of the brain of those diagnosed with schizophrenia.

While Torrey does review the historical contexts that have given rise to the shifting conventions of naming, he seems insensitive to the notion that his own current recommendations may become outdated and should therefore be more modestly proposed. Embedded within his “logical” approach (that if schizophrenia is a brain-based disease, we should call people with this disease people with schizophrenia) is a surprising obtuseness to the real issue raised by Hyde: Using these terms signifies a relationship, and this relationship ought to be coconstructed. One-sided adoption of any term used to name “the other” undermines the very relationship we are seeking to establish.

Hyde’s commentary, unquoted by Torrey, includes statements such as,

To clear the air, I have no favorite term or terms. At times in my professional life, I led the charge on “people first” language, and I worked with other advocates to change the...
words “patient” and “client” to “consumer” when that
seemed cutting edge. I stood with individuals who wanted
to be called addicts and with persons who just wanted to
be called Joe or Jane.
I worked with others to embrace the journey of recovery
and the many individualized pathways that journey takes.
I argued against the notion that simple behavior change
could solve all this; that our field is the only place in which
behavior out of the norm is what leads to treatment and
services more than an individual’s need. I also called people
on their inappropriate use of language such as referring to a
policy as “schizophrenic” or a person as a “lush.” And I will
continue to do so. (http://www.samhsa.gov/samhsaNewsletter/Volume_18_Number_2/DrHyde.aspx)

These words are far from what many a reader would
assume reading only Torrey’s commentary. Hyde recog-
nizes that our available terms are embedded within
a changing cultural context, and each is flawed or limited
in some way. (The commentary contains a link to discus-
sions regarding the terms patient, consumer, client, and
survivor.) This may be one reason why researchers have
found no consensus in what people designated by these
terms wish to be called. In a 2007 report on preferences
of 1827 people with serious psychiatric disorders, 39%
asked to be called client, 22% patient, 16% consumer,
11% survivor, 1% ex-patient, and 11% some other term.3

Torrey appears especially vexed by the term, “people
with lived experience,”

In reading the literature in which “people with lived experi-
ence” is used, however, it is apparent that the term is meant
to imply that the delusions, hallucinations, and other symp-
toms experienced by individuals with schizophrenia are
merely part of a spectrum of human experience. It is thus
an implicit refutation of the medical model of disease.

He is sampling very selectively. One can also find
examples of the use of the phrase that are firmly
grounded in the medical model (eg discussions of
trauma-focused care note how people with lived experi-
ence with schizophrenia are unusually likely to meet cri-
teria for Post-Traumatic Stress Disorder secondary to the
traumas frequently associated with the disease, such as
being hospitalized involuntarily). Surely, the phrase is
more often associated with the consumer/survivor move-
ments, which he appears intent on provoking, but Tor-
rey’s generalizations are not supported in fact because
of the many exceptions that abound as terms and phrases,
which are relative and come in and out of fashion change
in meaning.

Torrey’s essay does not settle but instead highlights
our predicament. If Torrey were only attempting to
make his own choices transparent, his response would
provide an interesting window into one medical perspec-
tive on naming. But he goes a step further in urging us all
to stop our hand wringing and adopt his perspective. This
issue is being raised because we lack consensus and
because passions are stirred by the names we call each
other. For now, while we lack consensus, we would
like to accept Hyde’s invitation to reflect on our own
and others’ choices in naming. We also advocate that
in our work, we respect the preferences of those being
named, thereby enhancing engagement in treatment
and demonstrating our respect for people as individuals
beyond the label of a disease.

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References
1. Torrey EF. Patients, clients, consumers, survivors et al: What’s
in a Name? Schizophr Bull. September 16, 2010; doi:10.1093/
schbul/sbq102.
samhsa.gov/samhsaNewsletter/Volume_18_Number_2/DrHyde.
3. Covell NH, McCorkle BH, Weissman E, Summerfelt T,
Essock SM. What’s in a name? Terms preferred by service