Challenges with Behavioral Health Services Research Data

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Introduction

Behavioral health services research is a multidisciplinary area of study that evolved during the 1980s. Those who participate in behavioral health services research examine the organization, financing, and delivery of behavioral health systems and services and the implications for cost, quality, access, and outcomes. While the broad field of behavioral health services research has continued to rapidly evolve over the past 30 years, there has been an accompanying exponential growth in the amount and type of data.

This chapter examines the complexity of data being generated by a multitude of individuals and organizations within the various areas of behavioral health (alcohol, drug abuse, and mental health) services research. It will also examine the role of technology in the complexity of services research and in accessing research databases. In addition, this chapter will identify some of the major databases in behavioral health services research and illustrate the complexity of collecting, organizing, and accessing information from a vast array of data collection sources.

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Behavioral Health System Challenges

The “de facto” behavioral health systems are very complex. They have numerous distinct sectors, organizational settings, financing streams, and differences in the type and duration of care. These systems are comprised of public sector services, private sector services, and increasingly hybridized services crossing over both public and private sectors (Hanson & Levin, 2013). The existing delivery systems provide acute and long-term care in homes, communities, and institutional settings. In addition, these systems provide services across the specialty behavioral health sector, the general primary care sector, and the voluntary care sector. In the United States, various other sectors that provide behavioral health services include the military, the Veterans Administration (VA), long-term care facilities, and the criminal justice systems (e.g., juvenile facilities, jails, and prisons) (Hanson, 2014).

Furthermore, there are multiple stakeholders involved in these systems, from providers to clients. There are numerous federal, state, local, and tribal agencies, professional licensing and accreditation organizations, managed care provider organizations, advocacy and regulatory agencies, and healthcare policy-making entities involved with impacting policy and services delivery. Stakeholders also include service users of all ages, their families, and their caregivers (including family members, advocates, guardians ad litem, and ombudsmen). Providers include clinicians, such as psychologists, psychiatrists, psychiatric nurses, social workers, mental health counselors, pastoral counselors, primary care providers, pharmacists, supportive services personnel, vocational and rehabilitation staff, administrative and clerical staff, and peer and lay workers, among many others who work in the prevention, intervention, and treatment of individuals with behavioral health problems. The number and variety of interested stakeholders, in turn, contribute to the complexity of collecting, maintaining, and accessing data in behavioral health service delivery systems.

Collecting data and the use of technology to develop information systems in behavioral health service systems are not new initiatives. Rosen and Weil (1997) described the use of electronic office management and psychological assessment software in clinical practice. Sujansky (1998) wrote the need for decision support tools and bibliographic retrieval systems, such as PubMed, to be embedded in the then-emerging electronic health record (EHR). Others have written the use of the Internet and national administrative data to collect behavioral health data, to address changes to existing services systems, and to establish mental health promotion campaigns (Andrade et al., 2014; Berry, Lobban, Emsley, & Bucci, 2016; Rhodes, Bowie, & Hergenrather, 2003).

Today, numerous types of networked informatics programs and applications handle in-house administrative tasks, such as billing and scheduling, as well as many functions within the managed care environment, such as certifications, authorizations, treatment plans, medication evaluation forms, treatment summary forms, and outcome assessments, and reporting requirements at the state and national level. Transportability issues surrounding innovations (such as treatment effectiveness and treatment context), standardization of terminology to reduce ambiguity, quality of care issues, and building improved behavioral health information and practice infrastructures continue to be addressed at the federal, tribal, and state levels.

As discussed throughout this volume, the often fragmented and rapidly changing policy and practice landscape exacerbates the lag between development and ultimate implementation of innovative, empirically tested practices which may take between 15 and 20 years for actual implementation (President's New Freedom Commission on Mental Health, 2003).

Further, the rapid change in behavioral health technology over the past decade has brought even more volatility to research and practice settings. For example, not only are "soft" behavioral health service technologies particularly vulnerable to problems of fidelity in implementation (Allen, Shelton, Emmons, & Linnan, 2018); there also are significant challenges to implementing and sustaining comprehensive behavioral health service programs at consumer, provider, program administrator, and developer levels (Aarons et al., 2012; Chaudoir, Dugan, & Barr, 2013; Gotham, 2004; Williams, Ehrhart, Aarons, Marcus, & Beidas, 2018).

Since challenges come from and across service, interorganizational, and consumer/advocacy sectors, intraorganizational and individual levels, and system/environment fit, specific data needed to address these challenges may become difficult to tease out, define, collect, or synthesize. These are universal challenges for nations, regardless of socioeconomic status of countries or levels of technologies easily available to their citizens. Today's multiple systems for the delivery of behavioral health services represent an increasingly diversified, interrelated, and complex information framework where data are collected, information is synthesized, and treatment, law, and policy decisions are made based upon the available data.

Behavioral Health Services Research Data

There are three main types of data in behavioral health services research: (1) primary data, (2) secondary data, and (3) tertiary data. Primary data are original, often "raw" data that can be in any format (e.g., numeric, spatial, textual, or interview data). Secondary data are analyses run on primary data that interpret, review, or synthesize original research. One example would be a report that repurposes a county infrastructure and services data for a neighborhood assessment of benefits and deficits. Another example is a summary report generated from the Centers for Disease Control and Prevention's (CDC) Web-Based Injury Statistics Query and Reporting System (WISQARS™) mortality and morbidity database. Tertiary data are the synthesis of data and secondary reports that place repurposed and/or collected data within a specific context within behavioral health services research. An example would be an agency report that included a series of articles from a peer-reviewed journal on formulary management with cost data from a report from Massachusetts on its public formulary.

However, behavioral health services research is complex. Often a research project or research data may address only a very specific portion of a larger issue. There are bits and pieces of data from multiple publishers/carriers/vendors across different time frames and in different formats. Further, not only are there numerous disciplines that work within behavioral health services research; there are different weights given to different types or elements of data and how these data may be used within those disciplines and professional practices. Numeric data, for example, in the form of actual datasets or predefined tables of variables, may be available for public use through the National Institutes of Health (NIH) federal data management requirements for research conducted under receipt of a federal grant (NIH, 2003, February 26) or through the Open Government Directive, a presidential memorandum signed by former President Barack Obama (2009).

While there are a significant variety of data sets in behavioral health at the federal level, they do not always exist in formats immediately usable for all individuals accessing these databases. For example, data are collected for a variety of federal data sets and organized into very different information formats (e.g., numeric, spatial, and textual) and contexts (e.g., clinical, statistical, and services delivery). The data are collected based upon specific objectives established for data collection and are based upon the specific plans for the utilization of that data set. Two examples are QuickFacts and FastStats.

QuickFacts, by the US Census Bureau, is a very thin slice of data that estimates selected characteristics of a population of a specific place at a specific point in time, as well as selected business and geographical data. However, data from a QuickFacts page comes from 12 different Census Bureau datasets: (1) Population Estimates, (2) American Community Survey, (3) Census of Population and Housing, (4) Current Population Survey, (5) Small Area Health Insurance Estimates, (6) Small Area Income and Poverty Estimates, (7) State and County Housing Unit Estimates, (8) County Business Patterns, (9) Non-employer Statistics, (10) Economic Census, (11) Survey of Business Owners, and (12) Building Permits.

A second example is the Mental Health FastStats from the National Center for Health Statistics. It offers four central data points: (1) morbidity, (2) physician office visits, (3) emergency room visits, and (4) mortality, with links to other reports that may also be of interest as well as other related agency data or sites. And while users can also look for FastStats on depression, there are no corresponding pages for schizophrenia, bipolar, or anxiety disorders. These examples reinforce some of the problems with publically accessible datasets and predefined tables, such as the granularity of data one may be seeking is not available through these resources; the combination of variables one is seeking may not be available; and the age of the data may make them unusable in a more current context. These problems plague many of the publicly available federal, state, and academic data.

Data also may be repurposed from primary data into secondary data analyses or tertiary data sources, such as reports and white papers. Information on how data are collected or characteristics of state behavioral health agency data systems for federal systems should always be reviewed to ensure the relevance and accuracy of the data for researchers and practitioners. Reports, such as *Characteristics of State*

Mental Health Agency Data Systems (Lutterman, Phelan, Berhane, Shaw, & Rana, 2008) or the most recent Mental Health Client-Level Data/Mental Health Treatment Episode Data Set (MH-CLD/MH-TEDS) for services provided through state mental health agencies, provide information on what researchers and practitioners may or may not find in agency data systems.

A basic EHR system, for example, may contain patient history and demographics, a patient problem list, physician clinical notes, a comprehensive list of patient's medications and allergies, computerized orders for prescriptions, and laboratory and imaging results. However, other documentation, such as the reports mentioned above, often include crosswalk tables, reporting methods, data dictionaries of included variables, federal definitions used in the reports, and behavioral health diagnosis codes. Federal legislation, such as the 45 CFR 170 (2011), addresses standards, implementation specifications, and certification criteria that apply to the EHR and EHR modules.

Public Domain and Public Sector Data

Federal and state governments are moving to digital-only data and documents available on the Internet. Public domain data and public sector data are not interchangeable (Abresch, Hanson, & Reehling, 2008). Public domain is a legal status, that is, items in the public domain are copyright-free. Public domain material may be modified, giving the person who did the modification both intellectual property rights and copyrights for the *modification*, not the *original* product.

Public sector data, however, are data produced by a public sector body. These data may either be in the public domain or be protected data. Governmental and institutional policies determine access, which potentially vary. Since constitutional, federal, or state law may govern access to public sector information, changes in access to government information, particularly after passage of the Homeland Security Act, potentially affect content and access (Abresch et al., 2008).

There are licensing and distribution issues associated with the use of primary and secondary data sets, such as data size, format complexity, and potential use restrictions. These restrictions may be due to copyright, access, or license agreements created by either public or private data producers. There are also intellectual property rights, liability issues, distribution methods, and data management practices to address in the acquisition, use, repurposing, and publishing of data and its results. There may be significant legal risks related to numeric and spatial data and analysis tools, including models, methodologies, and services, based upon the data and tools. Defective data used in decision-making may have consequences at a planning or population-based level of policy or practice. Since behavioral health services research often uses personal data obtained with informed consent, there may be restrictions and authorizations required for its use, with de-identified, aggregated data used in the final product.

Definitional Data

The first question in collecting data on behavioral disorders starts with definition and contextualization. In the United States, the authoritative guide to the diagnosis of behavioral disorders is the DSM-5 (American Psychiatric Association, 2013); the international standard for behavioral health diagnosis is the ICD-11 (International Classification of Diseases and Related Health Problems) in concert with the ICF (International Classification of Functioning, Disability and Health) to determine burden of disease (World Health Organization, 2017, 2018b).

While the ICD is used for reporting diseases, health conditions, and baseline statistics, the ICF is used to classify the functional components of health conditions. Also, there is language in the ICD-11 that suggests a relationship between the clinical effects of mental, behavioral, and neurodevelopmental disorders and the ability of individuals to function effectively across interpersonal, family, social, educational, occupational, and other levels of functioning. The ICF extends the context of disability (level of functioning) to environmental factors. This is an important consideration, as there is a continued global focus on the social determinants of health and how these determinants and their effects can be collected (Atkinson, Page, Wells, Milat, & Wilson, 2015; Hosseini Shokouh et al., 2017; Thomsen et al., 2013; Vest, Grannis, Haut, Halverson, & Menachemi, 2017; World Health Organization, 2016).

Behavioral Health System Data

Data can focus on an individual, an at-risk population, a facility, or a system. In the United States, behavioral health system data spans private and public providers (including both individual and organizational providers) of care, treatment and delivery, financing of care, law, and policy. It also spans medicine, social services, and rehabilitation. Behavioral healthcare data may address acute (or crisis) or long-term (maintenance) care. Although behavioral healthcare takes place in hospitals, providers' offices, community mental health centers, peer-run centers, religious organizations (pastoral care), academic health centers, jails and prisons, state or local government facilities, and private facilities, not all of these facilities are required to collect or report to or across local, state, regional, or national entities (see Fig. 1).

Common measures include behavioral health service history, severity and level of functioning, and quality assessment. Behavioral health service history is the patient's treatment history, defined as whether he/she had ever received behavioral health treatment prior to the current episode of care and, if so, where.

Severity and level of functioning measures an individual's level of everyday functioning and comparison with premorbid (before onset of diseases) functioning. Relevant aspects of daily living include daily living skills, social and recreational

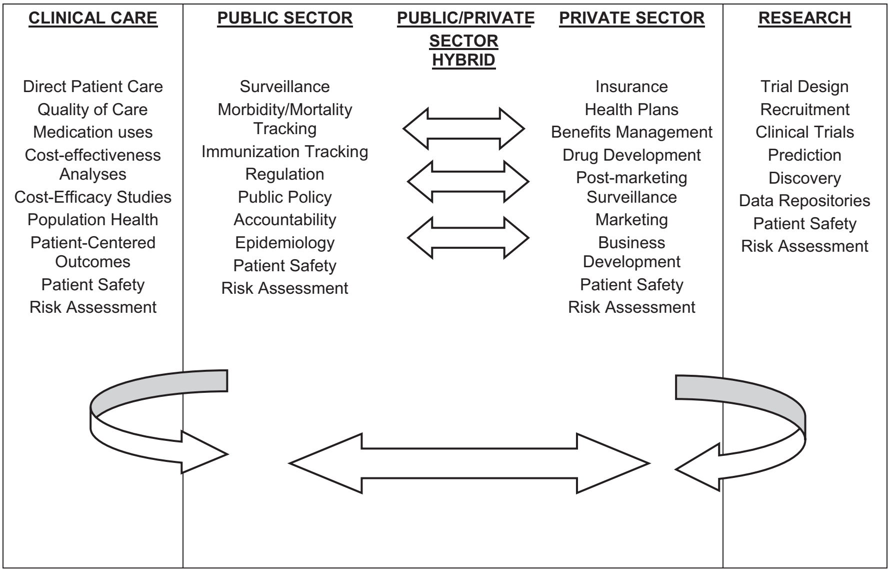

Fig. 1 Uses of behavioral health data across sectors

skills, and financial, vocational, interpersonal, and parental skills. The point of measuring level of functioning is to assess how much the illness has affected the person. This information is then used to design appropriate levels of psychosocial treatment and relevant social supports.

Quality assessment tools include individual treatment and system performance indicators, report cards, and consumer outcome measures, all of which use guideline fidelity measures (standards).

Data and assessment tools are comprised of domains that are issues, categories, or topics of interest. Indicators are discrete measurable activities, events, characteristics, or items that represent a domain. Measures are the instruments used to assess, evaluate, and measure an indicator.

In addition, behavioral health data is collected and used in a number of ways, such as client information systems and decision support functions. Such systems and functions would need to contain enough data to provide clinical consultations, update disease profiles, and create semantic relationships to map algorithms for diagnoses and etiologies. To achieve requires production rules, hierarchical classification trees, heuristic questions, and diagnostic criteria. Production rules would require probabilities to ensure findings are related accurately to diagnoses. Hierarchical classification tree(s) would represent disease categories and allow mapping to preferred, narrower, and current terminology. In addition, heuristic questions and evidence-based diagnostic criteria would be necessary to narrow the diagnostic hypotheses and conclude the clinical query. However, these and other elements are critical to ensure precision and relevance in discovery.

All types of data (computational, spatial, social, and environmental) increasingly are used in behavioral health services research. Integration of research into practice, the development of "best practices," fidelity in implementation, and the issues surrounding translational research require more and more data and use many different lenses and tools to view the data. Data mining large quantitative datasets, modeling real-life phenomena, and prediction or forecasting of long-term behaviors and activity are common activities in data collection and analysis.

Behavioral Health Clinical Data

Behavioral health clinical data exists in many forms. There is the raw data (i.e., patient-level fact data), knowledge data (best practices), aggregate patient data at the facility or system level, and surveillance data; any or all may be reported in varying degrees across local, state, national, regional, and global reporting levels. Data comes from medical records, administrative data, incidence data, patient satisfaction surveys, and more (see Table 1).

Linking client data from different health and behavioral healthcare sectors and agencies is necessary to assure the continuity of care, evaluation, and planning of behavioral health services. Integrating client, human resources, financial, services, and organizational databases create a foundation for both clinical and administrative data-based decision support and for programmatic and outcomes evaluation, program planning, and research. Reuse of behavioral health clinical data is found across numerous settings, from clinical, research, governmental, and business, and is often dependent on the source of data and the models used in the studies (Hutter, Rodriguez-Ibeas, & Antonanzas, 2014).

Three common models address cost-effectiveness, cost utility, or quality of life. Cost-effectiveness analysis (CEA) of treatment in healthcare facilities examines health outcomes more one-dimensionally, as in the number of psychotic events prevented or number of life years a patient gained. Cost-utility analysis (CUA) moves to two-dimensional measures, such as measures of change in patient survival *and* changes in the quality of a patient life. Health-related quality of life (HRQoL) measures often are multiplied by number of life years gained, which then generates the number quality-adjusted life years (QALYs) gained by the patient. These analyses also use patient survey data and cost data in a hospital or network. Table 2 shows a common CEA data collection and analysis process.

Data collection in healthcare facilities falls under process management (i.e., task/procedure processes, standardization, coordination, reorganization, using a cross-functional viewpoint examining strategy, operations, techniques, and people). This is particularly key as healthcare facilities, systems, and provider networks continue to automate their administrative processes to derive outcomes, quality improvement, and assessment data on patient care and business operations. However, three major challenges to the effective analysis, use, and decision-making with data are incomplete data and undefined management processes (Monto et al., 2016), as well as knowing what to count.

Table 1 Data and program types

	Community-based programs			
Data	Supported services	Evaluation	Treatment	Research
Admissions Patient history Caregiver/clinician reports Medical/lab tests Genomic profiles Treatment Emergency/crisis Medical records Patient satisfaction Surveys Accreditation Administrative Programmatic outcomes Patient report cards	Supported employment/education/housing Mobile care team Case management Hotline/crisis service	Consultation Client liaison Referral to service/treatment	Integrated care Specialty care Rehabilitation (vocational, physical) Emergency/crisis services	Day program Peer-run program Ambulatory care Case management

Table 2 CEA data collection process

	Patient	Facility	CEA analysis
First visit	First HRQoL survey	Patient data: personal, demographic, medical, etc. Data entry and storage	Calculation of scores
3 months posttreatment	Second HRQoL survey	Data entry and storage	Calculation of patient scores
			Calculation of difference between scores
			Calculation of QALYS
			Cost of treatment data
			Cost-effectiveness analysis

Knowing What to Count in Behavioral Health

One of the most challenging factors in collecting data on behavioral disorders is what data elements are collected. This ranges from setting, status as a primary or secondary diagnosis, levels of functioning, family, and societal burden. In 2001a, the World Health Organization's (WHO) *World Health Report* acknowledged the burden of mental, neurological, and substance use (MNS) disorders. Almost a decade later, the 2010 Global Burden of Disease Study confirmed that nearly one quarter of all years lived with a disability (DALYS) can be attributed to behavioral disorders (Murray et al., 2012; Vos et al., 2012; Whiteford et al., 2013). As part of the larger group of noncommunicable diseases (NCDs), MNS disorders account for more than 60% of deaths worldwide and frequently occur as comorbid disorders with both NCD and infectious diseases (Bahorik, Satre, Kline-Simon, Weisner, & Campbell, 2017; Charlson et al., 2016; Goodell, Druss, Walker, & Mat, 2011; Prince et al., 2007).

However, without addressing the relatedness of comorbid NCDs, infectious disease, and MNS, a paradox is created. MNS disorders are often less acknowledged in a global integrated health context, but often play a major part in a patient's quality of life, level of functioning, burden of disease, wellness, and years lived with a disability. Hence, achieving desired outcomes for global and national health programs becomes more problematic, especially when looking at the issues involved in gathering accurate data to answer the questions asked and yet to be asked.

How the ICD and ICF Are Used

The ICD is used extensively for the diagnostic classification of routine collection of population-based health information (morbidity and mortality) and for the mandatory statistical reporting required of WHO member countries. Depending upon the level of information required, the ICD ranges from a set of 100 codes to 10,000 codes which can be related to diagnosis-related groups (DRGs) and other case-mix systems. Categories include "diseases, disorders, syndromes, signs, symptoms, findings, injuries, external causes of morbidity and mortality, factors influencing health status, reasons for encounter of the health system, and traditional medicine," complemented by additional data on "anatomy, substances, infectious agents, or place of injury" (World Health Organization, 2018a). From a classification perspective, each ICD entity has a unique identifier (URI) and is grouped within and across hierarchies of groups, categories, and narrower terms. For a more detailed discussion on the elements of the ICD-11, see the WHO ICD-11 Reference Guide.

The ICD is increasingly used in the public health sector as a frame for (1) accessible services that address epidemiology, natural course of a disease, and disease burden of these disorders and (2) health promotion efforts to destigmatize mental illnesses (International Advisory Group, 2011). More recent discussions on the ICD suggest its importance in research, including formative, case-controlled, and clinical utility field studies, national diagnostic quality studies, and administrative data reviews (Gologorsky, Knightly, Lu, Chi, & Groff, 2014; Keeley et al., 2016; Nesvag et al., 2017). More importantly, the recent revision of the ICD (ICD-11) includes a "functioning properties" component that integrates the ICF activities and participation domains specific to disorders along with body functions and contextual factors (Escorpizo et al., 2013). The intent of the ICD-ICF cross-coding is to improve operationalization of an integrated disease-functioning model across health systems in all countries, from low resource to high resource.

Over the past 30 years, the ICD has been steadily integrated into national health policy and clinical care by the governments of WHO Member States (countries) through a number of stakeholder groups. These diverse groups include clinical care providers, healthcare coverage and reimbursement agencies, social and community support services, disability benefits agencies, payers of healthcare services, consumer and family advocacy groups, government agencies, criminal justice systems, educational systems, and judicial systems (International Advisory Group for the Revision of ICD-10 Mental and Behavioural Disorders, 2011). However, not all WHO Member States gather data from all of these trajectories of care.

Underreporting Prevalence

A major challenge in behavioral health data is underreporting. This means accurate and representative data on the prevalence of disorders is difficult to define. A number of resources are used to define prevalence, from medical and national records and epidemiologic and survey data to meta-regression modeling. However, raw data for countries that lack adequate collection and reporting infrastructure require comparisons that are created running sophisticated statistical models on epidemiologic data from neighboring countries. This affects studies, such as the Global Burden of Disease (GBD) studies, which rely upon epidemiological studies for its global and national estimates. These studies may not match data across age groups, countries, disorders, and epidemiologic parameters (Whiteford, Ferrari, & Degenhardt, 2016). To compensate, the GBD researchers use a specific statistical tool, Bayesian meta-regression, which (1) pools the epidemiological data available for a given disorder into a weighted average and (2) adjusts for known sources of variability in reported study estimates (Whiteford et al., 2016).

Since disorders and prevalence are not defined the same across researchers or nations, it can be confounding to compare data. For example, the GBD prevalence data on depression varies from the prevalence data used by the WHO, which varies from the US Centers for Disease Control and Prevention (CDC) prevalence of depression. Unlike the GBD and the WHO definitions of depression, the CDC includes anxiety as a subset of depression in its examination of the prevalence of depression (Whiteford et al., 2016).

Underreporting Population Subgroups

There is a relative lack of standards for collecting data on population subgroups. Numerous policy documents, such as the Sustainable Development Goals or Healthy People 2020, promote the elimination of health disparities[1] (US) or health inequities (WHO) as an overarching goal for the next decade. However, attaining this elusive

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[1] Health disparities include but are not limited to language; culture; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location (e.g., rural vs. urban); or other characteristics historically linked to discrimination or exclusion, such as race or ethnicity.

goal has been challenging. The lack of standardized data relevant to the many factors that identify vulnerable and at-risk populations makes it difficult to identify and implement effective actions to reduce specific health disparities. Health disparities/inequities are closely linked with the social and physical determinants of health (e.g., social, economic, and/or environmental factors) that affect health, level of functioning, and quality of life outcomes. A social determinants approach can help reframe the way policy-makers, public and private sectors, and the general public think about achieving and sustaining behavioral health.

Addressing Pathology and Etiology

Since their respective inceptions DSM (American Psychiatric Association, 1952); ICD (International Statistical Institute, 1893); ICF (World Health Organization, 2001b), these diagnostic standards have been the benchmarks for how behavioral disorders are diagnosed and "accounted" in incidence, prevalence, and treatment data. In addition, the ICD and DSM are used heavily in public health, clinical diagnosis, service provision, and specific research applications. However, their categorical and dimensional models fail to address the pathology and etiology of these disorders. The National Institute of Mental Health's Research Domain Criteria (RDoC) provides a different framework for understanding MNS disorders, including etiology, categories and dimensions, disorder thresholds, and comorbidity (Clark, Cuthbert, Lewis-Fernandez, Narrow, & Reed, 2017).

In the RDoC, etiology examines mental disorders from a multi-causality frame, in that these disorders develop from multiple influences (e.g., physiological, environmental, and societal). This parallels the SDH and social and behavioral determinants of health (SBD) frames. Mental disorders are complex, dimensional disorders, and different categories of disorders often have common, overlapping characteristics. Hence, categorizing mental disorders and their dimensions is problematic. Disorder thresholds are central in clinical decision-making; however, thresholds may vary greatly based on which component is under review (e.g., emotional, behavioral, cognitive, or physical) and can have negative or positive consequences (e.g., stigma or eligibility). Comorbidity denotes the simultaneous co-occurrence of two distinct disorders; however, Clark et al. (2017) suggest that co-existence of mental disorders may be a better way of framing the complexity and interrelatedness of mental disorders.

Data and Standards

An EHR documents (1) each episode (evaluation and treatment) of a patient's illness, (2) the plan for patient care and recovery, and (3) communication between all patient care staff. From an administrative perspective, the EHR is used for fiscal review and evaluation of the care and services, as it is a record of all events over time and locations. Since the EHR holds identifiable patient data, it is subject to legislative, regulatory, and confidentiality requirements at the staff, facility, provider, state, and national levels.

Accordingly, there are standards for the collection, coding, classification, and exchange of clinical and administrative data for behavioral health. Terminology, data interchange, and knowledge representation schema are the most common standards. Much like a controlled vocabulary, there are specific terms and concepts used to describe, classify, and code healthcare data, as well as to create relationships among the terms and concepts. Data interchanges encode healthcare data elements for exchange among facilities, providers, and networks. Knowledge representation schema codify how healthcare literature, clinical guidelines, and other information are used for clinical decision-making within the EHR or how other clinical or administrative documents link to or use information from the EHR.

The global emphasis on the social determinants of health and the Sustainable Development Goals (SDGs) has effects on the acquisition of a number of health indicators, especially to show national achievements of the SDGs. However, the success of a global health initiative depends on the development of a series of standards for national health infrastructures. A health record is but one tiny part of a national health infrastructure, which also must address interorganizational and cross-system communication, such as storage, processing, and transmission hardware and physical facilities, software applications, and network standards.

National and international standards for programming languages, operating systems, data formats, communications protocols, applications interfaces, services delivery, and record formats ensure compatibility and interoperability between systems and compatibility of data for comparative statistical or analytical purposes. Standards also establish a common ontology and ensure conformity assessment and usability.

Standards may also limit data collection, especially in remote or rural areas. National definitions of what constitutes a village, town, city, or metropolitan area vary significantly. Many national statistical systems provide data at the province or state level, with national definitions of what constitutes an urban area, a city, a town, an unincorporated area, or a village. If everything outside the "urban" class is designated as rural or the level of administrative oversight stops several steps above the village area, as may be the case in low- or lower-middle-income countries, then population data may be under- or overestimated. How a nation or locale defines a geographic area or its level of administrative oversight affects how it classes populations, settings, and workforce in its data collection and in final analyses of such. These "definitional caveats," which may or may not be stated in health or accompanying statistical reports, may affect our understanding of a national or locale.

Standards also play an important part in the development and use of monitoring and evaluation frameworks. National health information systems rely upon a range of population-based and health facility-based data sources, such as census data, household surveys, vital registration systems, public health surveillance, administrative data, health services data, and health system monitoring data, derived from local, state, regional, and national sources. With the development of the SDGs, a common monitoring and evaluation framework to strengthen health systems is essential (World Health Organization, 2010).

Health systems and research on these systems are often framed around financing, organization, payment, services delivery, and regulation (Hoffman et al., 2012, February 29). However, not all instances of the same theoretical framework are equivalent; hence, it is important to determine if there has been any divergence or convergence from or to a given standard framework or definition. Consider the case of universal health coverage (UHC). Although many countries rely on disaggregated survey data coupled with facility data, the survey data does not occur frequently enough to be a reliable indicator of current health sector performance. A focus on levels of health services coverage and equitable financial protection can provide indicators on how well a system is moving toward achieving UHC (Boerma et al., 2014).

From both global and national perspectives, syntheses of health data sources should focus on monitoring performance, harmonizing indicators and measurement strategies, and reconciliation of system disparities and discrepancies within and across systems. Harmonizing national indicators to a global measurement strategy may be problematic. To partner with WHO's monitoring and evaluation framework for health systems performance assessment and the SDG goals, US health data may need to be crosswalked to WHO, United Nations, and World Bank frameworks, among others. Since global indicators are used in comparative analyses, data quality assurance is critical across the breadth of diverse healthcare systems and policies. Data quality frameworks that can be used across national and global levels add complexity to the data collection, management, sharing, and conduct of analyses. Hence, it is critical to ensure for each metric or framework used there is consistency in the standards adopted to ensure objectivity and comparability over time and across localities, states, regions, and countries.

Implications for Behavioral Health

We talk about the importance of numbers in behavioral health services delivery, research, practice, and policy. Numbers are rhetorical devices, support implementation, drive policy, determine need, and determine success of treatment. Numbers are important. If you cannot be counted, you simply do not exist. A state (as in a country) has no obligation to you.

Examining the discussion on data presented above, we can articulate, with certainty, the following conclusions. First, data are difficult to collect, and despite efforts to systematize diagnosis, sociocultural differences may complicate the comparability of internationally collected metrics. Second, the lack of standardized data collection instruments, such as a unique patient tracking number, and differing care protocols make it challenging to maintain continuity of care, much less accurate data on trajectory of care or prevalence and incidence.

Health services research aims to be inclusive of all relevant information, both in terms of a grounded appreciation of the positive and negative benefits of a specific therapeutic intervention and a statement of the implications for the service. The need for reliable data on clinical and cost-effectiveness and a range of other contextual information require practitioners and academics to accommodate “research” as part of everyday practice.

In 2009, former President-elect Obama announced that large-scale adoption of health IT was a priority and that all US residents were to have EHR within 5 years. Federal legislation supported the electronic sharing of clinical data among healthcare stakeholders, which includes federal agencies responsible for the collection, analysis, and synthesis of such data. However, a decade after that announcement, the United States has not reached its goal.

There are multiple players, at many levels of government and in the private sector, who collect data and create information designed to answer specific questions or to fulfill reporting requirements. National standards, initiatives, and architecture try to make sense of their concerns and issues, focusing on infrastructure efforts, standards harmonization; certification; nationwide network, privacy, and security issues; and health IT adoption.

However, national data on behavioral health services in the United States remains incomplete at best. Not all behavioral health or behavioral health services data are collected, and in some cases, there are no formal structures or legal requirements in place to capture that data. To effectively handle just the linguistic properties of text, standardized language codes must support document longevity and interoperability of computing and network solutions. The same applies to the creation of network and platform protocols. Standards, whether data, semantic, or syntactic, apply equally to querying, searching, and accessing information from both vendor and the end-user perspectives. However, the issues of sharing information across numerous platforms and the variety of data types have not been made any easier. This is particularly true as we move to an increasingly global reporting on behavioral healthcare, services delivery, and systems design. There is a need to monitor global health regulations, health metrics (by country and perhaps even at a more granular level, such as county or region), disease surveillance systems, architectures, standards, and information systems.

There are numerous issues surrounding just standards development and linguistic congruence for health data. These data have implications on resource allocation, human development, quality of life, regional and economic development, and human security. Add additional issues of disability, functional outcomes, community reintegration, and resiliency. How many ways can these issues be defined and granulized into indicators locally and nationally in the United States, across professional groups, government agencies, consumer and family groups, and advocacy groups? Now consider how we reach consensus on definitions and indicators globally. The possibility of having accurate data, the same comparative indicators, and globally adopted outcomes literally comes back to decades of recommendations leading to the 2030 Sustainable Development Goals and similar national and regional initiatives.

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