Supporting implementation of evidence-based behavioral interventions: the role of data liquidity in facilitating translational behavioral medicine

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Abstract

The advancement of translational behavioral medicine will require that we discover new methods of managing large volumes of data from disparate sources such as disease surveillance systems, public health systems, and health information systems containing patient-centered data informed by behavioral and social sciences. The term “liquidity,” when applied to data, refers to its availability and free flow throughout human/computer interactions. In seeking to achieve liquidity, the focus is not on creating a single, comprehensive database or set of coordinated datasets, nor is it solely on developing the electronic health record as the “one-stop shopping” source of health-related data. Rather, attention is on ensuring the availability of secure data through the various methods of collecting and storing data currently existent or under development—so that these components of the health information infrastructure together support a liquid data system. The value of accessible, interoperable, high-volume, reliable, secure, and contextually appropriate data is becoming apparent in many areas of the healthcare system, and health information liquidity is currently viewed as an important component of a patient-centered healthcare system. The translation from research interventions to behavioral and psychosocial indicators challenges the designers of healthcare systems to include this new set of data in the correct context. With the intention of advancing translational behavioral medicine at the local level, “on the ground” in the clinical office and research institution, this commentary discusses data liquidity from the patient’s and clinician’s perspective, requirements for a liquid healthcare data system, and the ways in which data liquidity can support translational behavioral medicine.

Keywords

Data liquidity, Translational behavioral medicine, Health information systems

In the era of translational medicine, behavioral scientists are obliged to move beyond conceptual agreement to consider the “how to” of translation. In Medicine generally, barriers to translation, or “trans-

Implications

Practice: In a liquid data system, behavioral medicine clinicians stand to benefit from the greater availability of data that can help guide their clinical decisions and assist them in monitoring patients’ status and outcomes.

Policy: Large, population-based datasets could provide a strong foundation for healthcare policy decision-making and could be especially useful in areas such as behavioral medicine that warrant advocacy based on sound, generalizable evidence.

Research: A liquid data environment would make data more readily available for researchers to examine and analyze, aggregate, share and compare, and generally utilize for multiple research purposes such as identification of clinically important research questions and conduct of diverse research studies.

lation blocks,” (with “T” standing for “translation”) have been described at three phases of the research discovery-to-implementation continuum [1]. These blocks have been redefined so as to encompass behavioral medicine components: “T1,” traditionally defining impedance in moving from the “bench” (i.e., basic science laboratory) to the “bedside” (i.e., clinical application), can be redefined in behavioral medicine as the transition point at which new understandings gained through basic science are translated into new preventive or therapeutic behavioral interventions; “T2,” traditionally defining challenges in advancing new clinical interventions into practice, can be construed as the bottleneck where the results from behavioral medicine studies are translated into changes in behavioral medicine practice and healthcare decision-making [2]; and “T3,” traditionally referring to blocks in translating clinically effective interventions into changes in population level healthcare, healthcare policy, and systems of delivery, can be viewed, in behavioral medicine, as the obstacles to effectively integrating evidence-based behavioral interventions into the healthcare delivery system so that they reach the individuals and populations whose

health can benefit [3]. Examples of translational behavioral interventions that span these blocks have been presented elsewhere, such as the application of basic scientific understanding of diabetes and its management (T1) to develop behavioral interventions for diabetes self-management (T2) [4] and the cultural tailoring of these same interventions to most effectively reach identified populations in need (T3) [5].

National attention currently focuses on overcoming translation blocks through the use of health information technology (IT) and harnessing interoperable data and data systems, population-based datasets, and new types of data such as genomic and biomarker. Data liquidity—an attribute of data and the human/computer systems through which they flow—will be critical to resolving the general translational blocks throughout research and healthcare. In this commentary, we more specifically consider the role of data liquidity in realizing the goals of translational behavioral medicine.

GROWTH IN DATA AVAILABILITY

Behavioral medicine is rapidly advancing the science underlying its practice and developing new interventions based on this foundation. As a robust evidence base related to both the mechanisms of effect of behavioral interventions and the clinical effectiveness of these interventions grows, a host of corresponding requirements emerges. Behavioral interventions, such as smoking cessation strategies, increasingly rest upon a solid body of research evidence demonstrating their efficacy. Yet translational behavioral medicine will not become a reality until we can ensure that these evidence-based interventions move from the research realm into practice, and that they are, in actuality, (a) implemented in clinical practice of behavioral medicine, with sufficient quality to benefit individual patients, and (b) incorporated into the knowledge base supporting behavioral medicine, such that they inform care for relevant populations [6–9].

At the individual and the population level, behavioral medicine must answer a pivotal question: “How can we get the right care to the right patient at the right time?” [10] The answer, it would seem, is twofold: (1) by making available the right data related to behavioral interventions and outcomes, to guide clinical decision-making, and (2) by making those data readily accessible in the right format, one that provides them in a clinically meaningful context, secure format, and pragmatically useful way to healthcare providers, patients and families, healthcare organizations and health systems, and policy-makers.

One might argue that an ample supply of data exists in behavioral medicine to support clinical practice and public health. One could even contend that we have too much data, that a glut of potentially useful information actually impedes rather than expedites progress in clinical care. The mainstream press has explored the concept of data overload; *The*

Economist reported that the amount of information in the world today is growing at a compound annual rate of 60% and surpassed its storage capacities in 2007 [11]. In the scientific literature dating to 1998, Muir Gray described an “information paradox” [12] in which healthcare professionals have access to an abundance of information, but cannot find specific information when and where they need it [13]. In the age of comparative effectiveness research, we are encountering an “evidence paradox” whereby clinical research information is rapidly accumulating but not readily translatable to support the care of an individual patient who is frequently substantially dissimilar to the study population [14, 15]. This situation is, if anything, snowballing; the amount of digital information alone increases tenfold every 5 years [11]. Clearly, what behavioral medicine needs is not just more and better data; we need information systems that have been designed with the necessary cognitive support to make data accessible, easy to navigate, understandable, and actionable. In short, we need cognitively supported data liquidity.

DATA LIQUIDITY

The term “liquidity,” when applied to data, refers to the availability and accessibility of data to users, generally with specific reference to the flow of information through computer and other electronic interfaces. According to the Human Factors Engineering discipline, this liquidity requires that the information system: (1) employ a well-designed user interface to ensure that the user can efficiently assimilate information [16] and (2) provide reasoning and cognitive support to users through assistive functions such as searching, facilitation of changes in context (adaptive displays), and computational support [17]. In order to sustain data liquidity, human and computer information systems must be mutually supportive [18, 19]. In an ideal system, data will be readily *accessible* to appropriate users, regardless of their location, affiliation, or IT platform. They will be *interoperable*, that is, linked to other relevant data (e.g., basic science, clinical, demographic, behavioral) so that the user can explore associations that may guide healthcare decision-making. They will be *actionable*, in that they are accessed through convenient and intuitive search processes, provided in a user-friendly format, and supported by user tools, education, and technical assistance. And they will be *secure*, in that the protection of personal health information represents a central priority of the data system.

While not a requirement for liquidity, data reliability and quality are essential in order to support the application of liquid data to generate new knowledge. We must be mindful of the truism, “garbage in, garbage out.” As data become increasingly true to patient characteristics, outcomes information more plentiful, and datasets more complete, there will be a concomitant increase in the reliability of this liquid information that will stimulate new discoveries in behavioral medicine. For example, a 2010 *New*

England Journal of Medicine article documented the importance of acute pain management to reduce the risk of development of post-traumatic stress disorder (PTSD) after serious injury; this association was made possible by the military's ability to combine reliable data on the degree of trauma and the administration of morphine with longitudinal records on psychological health and assessments of PTSD [20]. The value of accessible, interoperable, high-volume, reliable data is indeed becoming apparent.

Health information liquidity is currently viewed as an important component of a patient-centered health-care system [21]. In such a system, which depends on the existence of electronic health records and other health IT infrastructure, patients' access to their own health data, as well as to other health-relevant information, will better inform them and will empower them to play a more active role in their healthcare. Patients' access to and use of available health-related information, both personal and general, is becoming increasingly relevant to behavioral medicine specialists as they become better integrated into the primary care setting. Currently, however, electronic health records are far from ubiquitous, and many patients lack access to their own data, though efforts to promote use of web-based portals are seeking to increase that access.

Attention to privacy and security is fundamental to promote a confidential system that patients can trust. Not only do patients demand and deserve a trustworthy system for their data, they also need to realize the value of readily available information to support personalized care. Patient education may be an important companion to data liquidity in this sphere. It can be used to address the challenges of limited health literacy by helping patients understand, interpret, and make use of their data to better manage their own health [22]. For example, education about the health impact of smoking, dietary behaviors, and lifestyle matched to an individual's current practices and beliefs may prove vital to improving personal health in conditions ranging from diabetes to depression [23]. Additionally, resources that direct patients to high-quality (evidence-based) versus low-quality websites, and web tools and sites that assist patients in interpreting the information provided, will be essential if patients are to take full- and beneficial-advantage of data liquidity. Patients themselves are demonstrating substantial willingness to access and use the health-related data that are available; the popularity of websites such as PatientsLikeMe [24], Microsoft HealthVault [25], and Google Health [26] indicates that patients are ready to participate in a liquid data healthcare system. On the other hand, it is not known how patients will cope with the complexities of genetic and genomic data that may be accessible to them in the near future [27].

In the provision of evidence-based behavioral medicine, equally important to data liquidity for patients is data liquidity from the clinician's perspective. Here, access to all data potentially relevant to the individual patient at hand will powerfully support clinical care and

decision-making; personalized medicine, though traditionally viewed as the tailoring of patient care using novel genomic and biomarker information, can be defined for behavioral medicine purposes as the provision of individual-specific care that takes account of the patient's health-related data in the context of an ecological model of health that includes multiple levels from cells to society [28]. For example, the care of an older individual experiencing chronic and severe pain may require a treatment plan informed by the patient's age, any physical disability, obesity, history of depression, history of medications, family history, employment history, place of residence, and social support. The ability of clinicians to view the clinical data in the larger genomic, phenomic, and psychosocial context, and the liquidity of this data across multiple levels, will ultimately allow healthcare providers to practice true translational, personalized, behavioral medicine. Simultaneously, it will support research functions such as hypothesis generation, comparative effectiveness studies, and cross talk between clinicians, clinical researchers, and basic scientists.

As with patients, clinicians may need substantial interpretive support to accompany data liquidity—particularly in the case of behavioral medicine interventions with which they may be marginally acquainted. For example, an oncologist considering a cognitive-behavioral therapy (CBT) for a patient with cancer-related pain may lack sufficient familiarity with this area to interpret data. Believing CBT to be effective for cancer-related pain, this oncologist may suggest a two-session information-based “CBT” intervention, though this minimalist version of CBT is unlikely to achieve the same effect as a high-quality, evidence-based intervention delivered over a longer time period by a practitioner with extensive experience in protocol-based behavioral treatments. If results for the patient are easily monitored and disappointing, the oncologist might conclude that CBT is ineffective for cancer-related pain, whereas in actuality the patient did not receive a high-quality intervention; rather than demonstrating limited potential of CBT to improve pain, the disappointing impact was due to poor quality of the intervention. This issue of data interpretation will become increasingly important as empirically validated behavioral interventions such as CBT are more widely disseminated and adopted, and as data systems make it possible to readily monitor outcomes of applied behavioral interventions.

REQUIREMENTS OF A LIQUID DATA SYSTEM

Data liquidity has multiple prerequisites including: semantic interoperability, ensuring that data elements and definitions allow for combining and comparing of data; syntactic interoperability, allowing exchange of information across different interfaces; and legal, regulatory, and security provisions. The establishment of these prerequisites will help ensure that the data are not misused or misinterpreted (e.g., due to differing uses of terminology) and are made available

as needed but without violating confidentiality or anonymity. Security is of premium importance. Fail-safe measures must protect the security of both personal health information and research data; these protections are required not only for ethical reasons but also to engender trust. Many behavioral interventions require the patient to divulge highly personal information and/or collect sensitive data; examples include a patient's report of prior instances of trauma or the results of psychological tests which contain highly personal information and which should only be interpreted by trained practitioners. With greater data liquidity, patients may be justifiably concerned that many healthcare providers will be able to electronically access their data, though they may lack the appropriate behavioral medicine training or security clearance to do so. Patients deserve reliable assurance about who will have access to their personal health information, and their faith in these assurances will likely determine their willingness to participate in behavioral interventions that contribute their data to a liquid data system.

Trust is important to clinicians, researchers, and other users of data in a liquid data system, as well as to patients. These individuals will only interact with the system if they have confidence that it will protect their data and/or will deliver data of consistently high quality to them. Data must be seamlessly interoperable across data types and data systems, with linkage largely happening in the background and resulting in useful associations and new knowledge. Data-related processes and data elements must be standardized to help establish, evaluate, and uphold data quality; fundamental to data liquidity is a universal set of commonly accepted, robust standards. These requirements, however, are necessary but not sufficient [29]. Other factors include tools to assist the user, including visual interfaces that help the user understand the information presented, dashboards that organize applications and activities, and filtering and sense-making mechanisms that assist users in interpreting data. These tools must facilitate convenient, intuitive, and intelligent use of data.

By definition, liquid data are available in a timely way. At least initially, however, not all data will be available in real time. It is important to ascertain which sorts of data behavioral medicine clinicians need to receive on a real-time basis and to ensure the immediate availability of these data. For example, a patient's self-reported suicidal ideation that began when embarking upon a mind-body program represents data which must reach the healthcare provider urgently. Other sorts of data may require a filter or quality assurance process before they can be accessed by general users; protocols for making these data available could help ensure appropriate timelines. Transparency, assuring that the source and accuracy of the data are known, will help users weigh the available information and judge its potential relevance. Governance and stewardship provisions, to codify practices related to use, sharing, pooling, analysis, and reporting of data and to oversee their

use, maintenance, and quality, respectively, will be critical. Finally and importantly, ethical issues will need to be dealt with both proactively and as they arise. Institutional Review Boards exist in nearly every research institution to oversee the management of research-related data; a similar ubiquitous entity may need to be defined and standardized in the realm of clinical data, perhaps in the form of a community advisory board comprising clinicians, researchers, and community members; representation from behavioral medicine will be important. The first step is local "data governance" and "data stewardship," that is, local rules defining standards, ownership, organizational interactions, and security. As we move toward a liquid data system, data governance committees and an evolving more global governance infrastructure could help anticipate, identify, and respond to ethical issues inherent in the concept and emerging in the realization of data liquidity.

The capacity of liquid data to support large-scale, well-powered, research studies in behavioral medicine is amplified tremendously by the integration of large-scale datasets, interoperability of local data with these population-based data, and availability of tools to facilitate use of linked data and interoperable data systems. Two examples relevant to behavioral scientists are Grid-Enabled Measures (GEM) and PopSci-Grid, both of which are integrated with the grid cyberinfrastructure developed by Cancer Biomedical Informatics Grid® (caBIG®) of the National Cancer Institute (NCI). GEM, an interoperable, dynamic, repository of behavioral and social science measures, allows behavioral medicine researchers to search for population health constructs (e.g., anxiety, depression, cancer prevention behavior, caregiver preparedness) and measures (e.g., Hospital Anxiety and Depression Scale), view metadata about these measures (e.g., validity, reliability, constructs, history, and usage) and download the measures. In addition, GEM provides a Web 2.0 architecture for participation [30] that enables researchers to upload alternative measures and constructs, add and edit metadata about, and rate and comment on measures and constructs under development [31]. GEM contains both cancer-related and non-cancer constructs and measures; its stated purposes include coordinating the behavioral medicine enterprise and facilitating efficiency in research. The PopSciGrid Community Health Data Portal, a proof of concept for cyber-enabled population health research, has been developed by the NCI Division of Cancer Control and Population Science; it is designed to encourage transdisciplinary collaboration and data standards and harmonization [32]. Currently in development with tobacco control as an exemplar, PopSci-Grid provides a framework that links national data from the Behavioral Risk Factor Surveillance System and Health Information National Trends Survey with economic data and smoking policy data; it uses geospatial and statistical applications to enable real-time access, analysis, and visualization. These components of caBIG® make data available to the behavioral

medicine community for examining disease, demographic, behavioral, and policy-level data [33].

DATA LIQUIDITY TO FACILITATE TRANSLATIONAL BEHAVIORAL MEDICINE

The fundamental purpose of translational behavioral medicine is to move behavioral science discoveries from the laboratory (be it a lab that engages in basic science, clinical research, health services research, or policy studies) into practice so as to improve outcomes for individual patients and populations [34]. Healthcare providers and population scientists alike must therefore have access to new findings and an IT and informatics infrastructure that enables them to place in this context data related to the individual patient and/or population of interest. An integrated data system should allow the clinician seeking to help a particular patient to: (1) identify the individual patient's needs, (2) access information on evidence-based/empirically supported biobehavioral interventions likely to benefit the patient, (3) manage and assess the patient's response to the intervention through real-time evaluation of its impact, and (4) assess the implementation and impact of the intervention over time.

Data liquidity can help the clinician at each step of this translational medicine pathway. First, with ready access to all relevant data such as mental health, physical activity, nutritional status, smoking history, psychiatric medications, and family support as well as clinical history, behavioral medicine practitioners can evaluate the patient's current complaint in the context of his/her full background. They can examine data types such as clinical data and data from previous psychosocial as well as biomedical care with an eye toward determining both the quality and the efficacy of prior care. Second, in evaluating the best behavioral intervention for the individual patient, the practitioner can search large, population-based datasets to identify and examine evidence for/against interventions that have previously been used for patients with similar characteristics. Timing of the intervention can again be guided by past experiences of like patients, retrievable through national datasets. Third, the routine collection of patient-level data and the liquidity of these data will allow the clinician to monitor the intervention's implementation and impact on multiple outcomes, determining both expected and unanticipated effects. A liquid system will help the clinician evaluate the patient longitudinally, including across transitions in care such as a transfer from one institution to another.

The availability of real-time data provides an opportunity to rapidly make evidence-based decisions on the efficacy of behavioral treatment, with the practitioner iteratively adjusting treatment for the individual patient based upon the results of intervention for that patient. This personalized, data-driven approach improves upon the traditional decision-making pathway in which, for example, a clinical psychologist must wait for the patient's weekly appointment to receive the patient's report of the effectiveness of a cognitive

behavioral strategy for insomnia. Here, the practitioner has access to data only at weekly intervals; upon reviewing the newly provided information in light of the patient's history, he/she makes a series of sequential decisions to continue, modify, or discontinue treatment. The process is lengthy, entailing time lags between action and evaluation. By contrast, in a liquid data system, the patient could provide data every morning, reporting on the previous night's use of the CBT strategy and sleep through an interactive voice response system. Data could travel in real time to a central data management system, with the system alerting the practitioner to problems as they arise and cuing him/her to modify the patient's regimen on a timely basis.

It is interesting to compare this liquid data approach to patient care, assessment, management, and research to the tradition of the single-case research design in behavioral medicine research [35]. In each case, there is a focus on the use of data acquired in real-time at the patient level to dynamically monitor response to treatment and iteratively adjust dosage and treatment plan based on this response. A liquid data system implemented in healthcare will support this "N of 1" approach simultaneously in the research and clinical spheres of behavioral medicine.

A liquid data system supports meta-analytic approaches in behavioral medicine as well. Consider a systematic review of behavioral interventions for cancer pain management. In earlier times, study features and aggregate results were hand-abstracted from published research reports to generate a common point estimate of efficacy [36]. Now, individual datasets from each study can be obtained, combined, and reanalyzed as a single dataset; data mapping must be done by hand, but aggregated results are clearly possible [37]. In the future, federated data aggregation models will eliminate the need to transfer datasets for aggregate analyses; information on interoperable common data elements will be readily available and meta-analytic approaches routine. Not only will the data support standard meta-analyses of efficacy across studies, but they can also be distributed to real-time, automatically updated, clinical decision support models, and cost-effectiveness models; an example is a real-time, self-updating, cancer pain economic model [38].

In summary, features of an agile data system that will support evidence-based translational behavioral medicine are: *clinicians' access* to linked datasets comprehensively containing the patient's data and to population-based data to determine which intervention is most likely to succeed for the current patient based on previous experiences of patients with similar characteristics; *patients' access* to their own data and to related data delivered through patient educational pathways to allow them to participate in healthcare decision-making; and *researchers' access* to demographic, clinical, and outcomes data so that they can develop hypotheses regarding new or existing interventions and design studies that will improve outcomes.

BEFORE DATA LIQUIDITY:

Sarah M, a 34-year-old woman, experienced persistent cancer-related pain after her left axillary lymph node dissection for her melanoma. She has been visiting Stan Smith, PhD, for counseling and, specifically, a personalized behavioral weight loss program.

Dr. Smith documents the visit using the hospital's old proprietary electronic health record; his clinic notes are in text form. While the electronic note provides adequate documentation to meet CMS billing requirements and to communicate Dr. Smith's findings and plan to the care team, the data generated during the visit are stagnant. They cannot be searched, codified, or repurposed.

Researchers who want to summarize the impact of obesity/weight loss on cancer pain must manually abstract data from this electronic health record onto paper case report forms, and enter information into a database to facilitate analyses; this database cannot be linked to those of other research projects. The hospital's quality improvement team must follow similar processes.

Information entered into the clinical note in July does not auto-populate the August note. Instead, Dr. Smith cuts and pastes the July note into the August template and edits his typing. His clinical care cannot efficiently contribute to better understanding of healthcare delivery, since his notes are not easily accessed by CMS; only his billing data are efficiently transferred to CMS and back.

JUST THE STARTING POINT...

Substantial work lies ahead before we achieve true data liquidity. Across the USA, institutions, health systems, innovators, and policy-makers are striving to accomplish the various tasks necessary to make data readily available—while also maintaining privacy, security, appropriate use, and quality.

For practicing clinicians in behavioral medicine, certain inherent requirements must be met in order to achieve the promise of data liquidity. First and foremost, we must achieve consensus on the structure of clinical documentation, clinical processes, and the data elements supporting them. The components of a clinical note (problem statement, assessment, intervention) must be coded consistently. With the Office of the National Coordinator demanding meaningful use by 2015 [39], behavioral medicine as a community must be prepared to demonstrate its viability and importance and to prove its role through Accountable Care Organizations, made possible through Health Care Reform. Data liquidity and common data standards across the discipline will be a requirement for these demonstrations of relevance at the national level.

The potential for data liquidity to support evidence-based translational behavioral medicine is huge; before/after text boxes illustrate the greater efficiency and coordination made possible by a liquid data system. Access to relevant data will help determine the best biobehavioral intervention for the individual patient and for patients with specific characteristics. For patients seeking care, data liquidity can help identify possible biobehavioral interventions that may benefit them, prompting them to educate themselves further and to participate in clinical decision-making. The evidence base available to support future translational behavioral medicine will be continuously strengthened by health IT and data processes that feed patient-level data and outcomes back into growing datasets (which are interoperable with other datasets); data liquidity will ensure that these resources will indeed help guide future clinical practice.

As a final note, it is important to remember that data liquidity does not obviate the important roles for clinical judgment, ethical reviews, expert consensus, and evidence-based guidelines—all of which should be called upon in concert with the growing wealth of available data. The consideration of all of these complementary perspectives will yield a more sophisticated, multidimensional assessment of the best treatment strategy for the individual patient.

AFTER DATA LIQUIDITY:

When Sarah M visits Dr. Smith, her clinical note is generated from an amalgamation of codified data elements, each discretely documented by Dr. Smith. The data elements have been agreed upon by clinicians and researchers in Behavioral Medicine; data standards ensure interoperability across data systems. Dr. Smith provides text comments that supplement and provide important contextual information for the discrete data which he enters. A report joins the discrete coded information and text information into an informative clinical synopsis for his use in subsequent visits. Data security controls ensure that privacy is maintained; only appropriate clinical, research, administrative and regulatory personnel can access Sarah's personal health data.

When Dr. Smith sees Sarah next, relevant information from July's note automatically populates the August note. Dr. Smith updates the note with Sarah's medications, allergies, weight, and self-reported behavior. This new information enters a database available to researchers, quality improvement staff, and CMS; it is stored for analyses, data needs, and quality assessment (QA). QA results and outcomes data are available to clinicians making treatment decisions for future patients.

The data system can generate various reports, from patient level graphs of Sarah's weight loss and other health measures to health system-level summaries; traditional analytics (e.g., descriptive statistics and graphs). Newer visualization techniques (e.g., dashboards, clinical decision support tools) use the same data elements. At the health system and national level, the data are available to demonstrate Behavioral Medicine's value in healthcare.

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