

Measuring and Improving Patient Experience in Care for Persons with Advanced Illness: Methodology Matters

By Bruce Vladeck, Erin C. Westphal, and Gery W. Ryan

As health care providers throughout the United States increasingly focus on improving care for persons with advanced illness, measuring and understanding patient (and family) satisfaction with care becomes especially important.

Patient satisfaction, of course, is increasingly incorporated into all sorts of quality measurement and improvement processes, but it has special significance in caring for those with serious, life-threatening illnesses. Both the patients' problems and the care they receive are particularly complex and multidimensional.

In caring for patients for whom a cure is unlikely, quality of life and patient satisfaction with care take on additional importance. As a result, substantive, continuing engagement of patients and their families in decision making about care becomes a goal of the caring enterprise, not just a means to other goals.

And unlike many other health services, care of those with advanced illness is not a one-time intervention; caring occurs, and changes, over time.

Precisely because fully characterizing and measuring patient and family satisfaction is so central to quality improvement in care of advanced illness, it is important that measurement strategies be sufficiently sophisticated, adaptive, and multidimensional. "Off the shelf" measurement instruments or processes, no matter how well-tested or validated in other areas of health care, are not likely to provide the depth of understanding or information about the range of issues that should concern those providing, paying for, or promoting care of the seriously, chronically ill.

Our starting principle is that the tools employed (for almost any purpose) must be suited to the tasks at hand. Care of patients with advanced illness is especially challenging for individual clinicians and health care organizations because it is complex, multidimensional, continuing, and suffused with issues of individual autonomy and choice, function and feeling, and often – literally – life and death. Seeing care processes from the patients' perspective is a formidable challenge.

This paper seeks to define a strategy for developing effective, broadly-based measurement and understanding of patient satisfaction in care for advanced illness, both as a measurement of quality and, perhaps more importantly, a continuing tool for continuous quality improvement. In doing so, it builds on and attempts to summarize a series of activities undertaken by The SCAN Foundation (Foundation) over the last several years as part of a broader effort to encourage the development of innovative health care delivery programs aligned with the principles of what the Foundation has come to call care based on the principles of "Dignity-Driven Decision Making" (DDDM).

We begin with a methodological discussion, first of the principles of program assessment – of which quality measurement is one form – followed by a consideration of the relative advantages and disadvantages of "qualitative" or "quantitative" approaches to measuring patient satisfaction and other characteristics of the health care system. We then provide a brief description of the principles of

DDDM-based care and its core components and the implications these components have for measuring patient satisfaction. That is followed by a brief assessment of the strengths and limitations of current patient satisfaction measurement approaches. Finally, we recommend a multi-step strategy for the development of satisfaction measures that are more appropriate for assessing DDDM-based care, while incorporating existing measures into a more comprehensive evaluative process.¹

The Multiple Faces of Program Assessment

The measurement of patient satisfaction in health care, and indeed of the quality of care in health care services more broadly, can be understood as one form of what is often described in the social sciences as program assessment. At its core, program assessment is the process by which program funders, administrators, and providers come to understand what is working, what is not working, and why (from the perspectives of the program's implementers as well as its end-users). To this end, program assessment is best seen as a type of learning in that it: (a) often serves multiple purposes; (b) is an evolutionary and accumulative process of acquiring knowledge; (c) can be useful in both its formal and informal forms; and (d) can be treated as a single learning event or ongoing and life-long learning processes. We describe each aspect below.

First, program assessments can serve multiple aims depending on the maturity of the program. For example, during the

early stages of a program's development, assessments may focus simply on developing initial mechanisms for tracking the program's performance (e.g., *monitoring*) or be used to identify problem areas and potential solutions to improve the program (e.g., *process assessments*). As programs mature, more precise and systematic assessments may be required to track performance over time or to compare performances across programs, sites, personnel, or patients and families. Finally after reaching maturity, program assessments may be used to estimate the program's effectiveness and determine whether it should be continued or not (e.g., *summative or impact assessments*). We cannot overemphasize that for assessments to be effective and useful, they need to be aligned with the development of the program. Conducting summative or impact assessments before a program is mature are like assessing a child as an adult. On the other hand, population needs and health care technologies evolve continuously as well, so even when programs are mature enough to rely on relatively sophisticated summative assessments, it may still be desirable to provide for additional less formal monitoring.

Second, program assessments, like all learning endeavors, typically begin with simple and anecdotal observations and hunches that accumulate and evolve into more precise measures and more complex understandings over time. Although often forgotten, such a grounded understanding of the fundamentals is the basis for all scientific development. Without the initial exploratory and detailed descriptive work of natural history, for example, our complex understanding of

¹Before proceeding, it's necessary to inject a quick editorial note. While the concept of patient satisfaction is widely understood, in the care of persons with advanced illness (as well as other instances), the definition of "patient" often becomes a bit more complex. Many individuals with serious illnesses become extremely dependent on family members or other caregivers. At the most basic level, this dependence sometimes extends to simple communication with third parties, but such issues as relationships with providers and decisions about care, which are important dimensions of satisfaction, also often involve a dyadic or even more complicated patient-caregiver combination. From the measurement point of view, it's critical to distinguish between a caregiver who simply mediates communication between the patient and observer and one who is an intimately-involved "stakeholder" in addition to, or separate from, the "translational" role. There will be instances in which the patient is highly satisfied and the caregiver dissatisfied, or vice versa, but more often satisfaction or dissatisfaction will be refracted through their relationship. Nonetheless, for purposes of manageable writing, we use the term "patient satisfaction" throughout this paper to refer to both individual and "compound" patients.

biology today would not exist. Researchers who believe they can skip these initial exploratory and descriptive steps in assessing new programs do so at their own peril. The history of science is littered with examples of measures and theories that were developed in one area and applied to another area only to find out later that they were not valid.

Third, assessors can learn about a program in all sorts of ways, from talking informally to end-users about their experiences, to administering standardized satisfaction surveys, to conducting formal randomized control trials. Unfortunately, most researchers assume that formal (and more precise) assessments are inherently better than less formal (and less precise) assessments. From a learning perspective, the formality and precision of the assessment should match the precision needed for the task, question, or decision the assessment is designed to address. For instance, if the task is to identify the range of things end-users like and dislike about the program and prioritize those that are most salient to the group, then a relatively low level of precision is needed. On the other hand, if the task is to determine which of two very expensive interventions will be given to all end-users, then a much higher level of formality and precision is needed.

The interrelatedness of program assessment methods and goals is also extremely relevant to a world of health care delivery in which “patient-centered care” is a value to which lip service is increasingly devoted. As health care organizations struggle with the operationalization of that concept, it is hard to see how an enterprise can be patient-centered if mechanisms for eliciting the views and responses of patients are not integral to everyday operations, or if those mechanisms are too heavily routinized and provider-centric. Again, in care of individuals with advanced illness, a continuing dialogue with patients and their caregivers is not only a valuable tool

of performance assessment; it is also a central operational process in and of itself.

Similarly, program assessments can be seen as well-defined set of tasks with a clear start and end-points, or they can become part of continuous quality improvement processes. In the former case, the assessment is designed to address a particular issue or contribute to a particular decision and therefore has a limited time frame. In the latter case, the program assessment morphs into being part of the program itself. Here program assessors establish the kinds of metrics that should be collected on a regular basis, determine how these should be best analyzed, and create structural mechanisms through which the analysis can be used in future decisions. In that way program assessors move from advisors to decision makers, to being agents of change in a program’s systemic development.

What Do We Mean by Qualitative and Quantitative?

The desirability of serving multiple ends in the measurement of patient satisfaction in care for advanced illness suggests, at the outset, that multiple measurement techniques may well be appropriate. But it’s still important to identify the major attributes of those techniques.

When deciding whether to use qualitative or quantitative tools, program evaluators are often befuddled by the semantic ambiguity and disciplinary parochialism that characterize the ongoing “qualitative vs. quantitative” debate. Semantically, “quantitative” and “qualitative” are adjectives which attribute the characteristic of quantity or quality to the noun they modify. When the terms are used to describe data, however, they have a more ambiguous meaning when applied to questions, interviews, data analyses, approaches, and research. To address this confusion, we will try to clarify what we mean by qualitative and quantitative and how these terms are applied to data, questions, interviews, analyses, and research approaches.

Quantitative and qualitative data.

Quantitative data refers to a datum that indicates quantity. Someone's age, their weight, the response on a Likert scale are all quantitative data because each presumes that there is some underlying scale and that the datum indicates a point on that scale. The scale does not need to be precise to be quantitative. *All, some, and none* are quantitative data, too. In measurement parlance, quantitative data are those that conform to an *ordinal, interval, or ratio scale*. In contrast, *qualitative data* refers to data that do not have an inherent quantity. *White, Black, Hispanic* are qualitative data just as are *red, green, blue, Chicago, New York, and Los Angeles*. Despite being numbers, zip codes such as 90034 and 05431 are also qualitative data because they do not imply an underlying scale – 90034 is neither more nor less than 05431. In measurement parlance, qualitative data are those that conform to a nominal scale – indicating that they do not imply an underlying quantitative scale or continuum. Qualitative data, however, are more than just nominal measures. Most qualitative data come in the form of *nonvariable* data – whole, multidimensional chunks of texts, sounds, images, and material stuff. Such data can capture, for instance, the complexity of a patient's account about their last encounter with a care provider or the nuances embedded in a patient's report of how their illness has progressed and the impact it has had on their life. There are no advantages or disadvantages intrinsically associated with qualitative or quantitative data. There are simply tradeoffs between the need to have data to illustrate complexity and detail and the need to have data to count frequencies and make comparisons.

Open- and closed-ended questions.

When applied to questions, the terms "qualitative" and "quantitative" typically do not mean that the questions exclusively generate qualitative or quantitative data; but instead these terms indicate whether the

There are no advantages or disadvantages intrinsically associated with qualitative or quantitative data. There are simply tradeoffs between the need to have data to illustrate complexity and detail and the need to have data to count frequencies and make comparisons

questions are *open-ended* or *close-ended*. Open-ended questions allow respondents to answer in their own words. Closed-ended questions force respondents to select from a fixed set of responses (i.e., response categories). Since most responses to close-ended questions are stored in a spreadsheet or data base, they are assumed to be quantitative. The confusion comes in that qualitative questions (i.e., open-ended) and quantitative (i.e., closed-ended) questions can generate both qualitative and quantitative data. For example, the open-ended question, "How would you describe yourself?" could generate the following response: "I'm Joe. I'm 52 years old and I live in Los Angeles." Likewise, one can ask close-ended questions that are limited to quantitative responses ("How long have you been employed here?") or limited to qualitative responses ("What country are you from?").

Open-ended and closed-ended questions have clear advantages and disadvantages. If you know very little about a topic, for all practical purposes you must use open-ended questions to learn anything about it. Open-ended questions allow you to find what you don't know. They are easy to ask, but tend to be difficult to analyze in terms of time and effort required for coding and interpreting the results. In contrast, closed-ended questions are useful for making detailed comparisons because all responses are forced into the same framework. Although open-ended questions can be used to make comparisons across respondents, the comparisons are likely to be less precise than when using responses from closed-ended questions. Close-ended questions

and their accompanying response categories are more difficult to formulate than open-ended questions but usually require much less effort to analyze.

For these reasons, regulatory bureaucracies both private (such as the Joint Commission or Residency Review Committees) and public (Centers for Medicare and Medicaid Services (CMS)), frequently prefer close-ended questions, since they appear to be much more “objective,” are more easily aggregated across very large numbers of regulated entities, and generally produce results with which the legal system is comfortable. Courts and administrative tribunals are more likely to agree that standardized measures based on standardized questions are “objective,” and that the administrative actions they are employed to support therefore meet the legal threshold of being neither “arbitrary” nor “capricious.” On the other hand, the orientation of the legal system to addressing one case at a time is one of several reasons why courts are frequently more accepting of qualitative evidence than are most government agencies.

Structured, semi-structured and unstructured interviews.

The terms qualitative and quantitative are also confusing when applied to interviews. When researchers refer to qualitative interviews, they are usually referring to unstructured or semi-structured interviews that typically consist of a series of open-ended questions. When researchers refer to quantitative interviews they are typically referring to highly structured interviews that typically consist of a series of close-ended questions. The qualitative/quantitative terminology blurs the key distinguishing characteristic of interviews in that they are *structured* (where people get the same questions in the same order), *semi-structured* (where people get more-or-less the same questions in sometimes different orders) and *unstructured* (where questions and order may vary significantly from one interview to the next). In fact, the amount of structure and

the type of questions asked are completely independent of each other. One can create a completely structured interview composed of open-ended questions (often referred to as *questionnaires*) as easily as one can create a completely structured interview composed of closed-ended questions (often referred to as a *survey*).

Like any methodological technique, including more or less structure in an interview has advantages and disadvantages. Unstructured interviews are good when you are in early exploratory mode and you want to let your respondent lead you into new areas. Unstructured interviews, however, are less useful for making comparisons across people as the interviewees rarely answer all the same questions. We typically use unstructured interviews when informally collecting information (for example, in participant observation, in which the researcher is also participating in the activity being studied) or when you know you will be able to interview a person multiple times. Semi-structured questions are ideal for allowing interviewees to lead you to new areas that you weren't aware of while simultaneously providing enough structure in the interview to make meaningful (though not necessarily precise) comparisons across interviews. Finally, structured interviews are used when the primary purpose of the work is to make systematic and precise comparisons across interviewees. This is important when the objective of the study is to estimate population parameters or when comparisons across people, space or time are required.

Qualitative and quantitative analyses.

When “qualitative” and “quantitative” are applied to the phrase “data analysis,” it is unclear whether the adjectives modify the noun “data” or the noun “analysis.” A more nuanced understanding of the different types of data analysis could be represented by a two-by-two table in which qualitative and quantitative

data represent the rows and qualitative and quantitative analysis represent the columns (Bernard and Ryan, 2010). The four resulting cells produce the: (a) *qualitative analysis of qualitative data* – the exegesis or interpretation of a text’s meaning; (b) the *quantitative analysis of quantitative data* – the statistical and mathematical algorithms for identifying and testing patterns; (c) the *quantitative analysis of qualitative data* – the systematic coding of qualitative data to test hypotheses using statistics and other mathematical algorithms; and (d) the *qualitative analysis of quantitative data* – the interpretation of quantitative results such as the meaning of a graph or significance of $p = .051$. Analysis techniques are like tools in a tool box. They are not better or worse than each other; they are simply different and serve different functions.

Exploratory, descriptive, comparative, explanatory and confirmatory approaches.

Finally, when “qualitative” and “quantitative” are applied to approaches or research, the adjectives tend to differentiate between exploratory versus confirmatory research goals. When researchers use the phrase *qualitative research*, they are typically referring to research that uses: (a) unstructured or semi-structured data collection techniques composed primarily of open-ended questions; or (b) large secondary datasets of qualitative data (e.g., speeches, newspaper articles, letters, etc.). In either case, the phrase *qualitative research* usually also means that main purpose of the research is exploratory or descriptive and that the researcher is trying to identify meanings, find patterns, and develop hypotheses or preliminary models. In contrast, when researchers use the phrase *quantitative research*, they are typically referring to research that uses: (a) structured data collection instruments composed primarily of close-ended questions; or (b) large secondary datasets composed of quantitative data. In either case, the phrase *quantitative research* is usually designed to estimate population

parameters (e.g., What percentage of people believe X?), to make comparisons across groups, or to confirm specific hypotheses. But the common juxtaposition of qualitative and quantitative approaches and research presents false dichotomies. Researchers can use quantitative data sets to explore and find patterns (e.g., exploratory factor analysis) and describe phenomena (e.g., univariate statistics). Researchers can also use qualitative data sets to make comparisons (e.g., word counts and free lists analysis) and to test hypotheses (e.g., classic content analysis). Instead, it would be more productive to consider the fundamental objectives of each approach and label them as *exploratory*, *descriptive*, *comparative*, and *explanatory* or *confirmatory*. As with the different types of data analyses, no research approach is better or worse than another. They just are approaches trying to address different kinds of research objectives.

DDDM-Based Care and Assessing Patient Satisfaction

All these methodological considerations come into play in addressing the question of how to best measure and characterize patient satisfaction with Dignity-Driven Decision-Making based care. Dignity-Driven Decision-Making (DDDM) is a philosophy of care for people with advanced illness – defined as one or more continuing, debilitating or potentially life-threatening medical conditions that result in functional impairments and impact a patient’s day-to-day life. Many providers throughout the nation are utilizing methods of care that are aligned with this philosophy. At the core of DDDM-based programs is a commitment to shared decision making between patients and providers that may be supported by formal processes, but the essence of which is a continuing, substantive, trusting reciprocal relationship between patient and provider. In order to support such relationships, DDDM-based

programs generally provide a specific set of services – medical and community-based – to a targeted population. These models are often rooted in the community, and employ a team of providers (e.g., physicians, nurses, social workers, etc.) who work in partnership with the patient and his or her family to develop and implement plans of care that promote the patient’s medical care and personal goals. Preliminary evaluations have shown DDDM-based care programs to be effective in advancing the Triple Aim of improved patient care outcomes, improved population health, and reduced costs. (Vladeck and Westphal, 2012)

Discussions of “patient-centered” care often incorporate an implicit model in which the patient and provider are two autonomous, if asymmetrical actors, and in which the provider is guided by the explicit wishes and concerns of the patient. Such a model may work perfectly well for routine care for routine medical problems, but in cases of advanced illness the inherent complexity of care, the unavoidably high emotional content, and the need for continuing, ongoing care over time require a more complex relationship, and more sophisticated means of characterizing it. During a focus group with providers of care, a participant eloquently captured the critical qualitative question from the provider’s perspective: whether “...we know you well enough to anticipate your needs, what you’re worrying about, what your social limitations will be; do we know enough about you to actually help you where you are... (personal communication, Elizabeth Loggers, MD)” Understanding whether patients’ perceptions of the relationship are the same as theirs is thus central to provider effectiveness in DDDM-based care.

In programs that care for patients with advanced illness, including those that conform to the principles of DDDM-based care, efforts to continuously assess patient satisfaction are essential and serve multiple objectives. First,

ongoing assessments of patient satisfaction help program managers and clinicians understand whether their instincts and beliefs about how well they are serving individual patients and their caregivers are correct. Second, such program assessments can help those clinicians and managers understand what is working well in what they are doing and what isn’t, and how they might improve the quality of services they are providing, increase patient satisfaction, and improve efficiency in meeting those goals. And finally, program managers will require systematic assessments to demonstrate that their approaches to care are as good as, or better than, prevailing existing practices, both to justify the energy being devoted to maintaining their programs, and to make the case that they deserve support from both internal and external stakeholders, including payors, regulators, and other health professionals.

In 2013, as part of its efforts to understand patient satisfaction in DDDM-based care, The SCAN Foundation supported a series of focus groups (a classic method of exploratory research), conducted by Lake Research, of patients and family members who receive care from organizations which share a commitment to DDDM principles. The goal of the focus groups was to determine how patients and families defined quality in those programs and how that contributed to their success. Lake Research identified five components of the care experience that were central to patient and family satisfaction. These included access to care, care coordination, satisfaction with particular services, relationships with providers, and patient education and decision making – which patients clearly saw in the broader context of their relationship with their providers. Of those components, the provider relationships were far and away the most important.

In DDDM-based programs the principal provider, from the patient’s point of view, is often not a physician, but another health

professional working within a multi-disciplinary team. The identified point of contact, therefore, can be a physician, nurse, social worker, or other care team member. Access to this point of contact and their seamless communication with the rest of the team (care coordination) are also highly valued.

The right kind of relationship with the right kind of provider facilitates the patient's involvement in decision-making and control over how their care is provided, often without any explicit discussion of goals or preferences; the patient and provider learn together over time. For many patients, what is most important is not at all clinical. Being supported by a team with a plan of care that was centered on personal goals - e.g. participating in a major life event like a wedding - rather than clinical goals was essential. Lastly, the concept of time is critical. Both the medical condition and the emotional state of patients with advanced illness can dramatically change over time and are not always correlated with one another. Understanding experiences and how they change over time needs to be a part of the assessment.

These findings suggest that effective measurement of patient satisfaction with DDDM-based care would require a reasonably nuanced and multidimensional understanding of patient/provider relationships, and of how decision making about care took place within those relationships, along with methods that would account for the fact that relationships – as well as patients' needs, feelings, and capabilities – evolve over time.

Existing Approaches to Measuring Patient Satisfaction

For the federal government's purposes, the primary tools for assessing patient satisfaction

are the various forms of the Consumer Assessment of Health Plans and Services (CAHPS). Originally developed as a means of evaluating the performance of managed care plans, versions of CAHPS have since been developed to compare the performance of clinicians and group practices, hospitals, and home care, and a version for hospice care is under development. All of the CAHPS versions are close-ended, quantitative surveys, generally mailed to the patient shortly after discharge (or, in the case of outpatient providers and health plans, once a year), although they can also be administered by phone. Hospital scores on CAHPS now account for 40% of hospitals' total quality scores, which in turn are tied to bonuses or penalties of up to two percent in Medicare payment. Several commercial companies also offer their own, similar surveys. CAHPS scores have also been shown to correlate with some, but not all, more clinically-based measures of health care quality.

Although CAHPS measures are important tools for making comparisons across units (e.g., plans, hospitals, providers, etc.) and over time, they are not specifically designed to help providers assess their interaction with specific patients and their families, nor are they specifically designed to help with a program's quality improvement efforts. As has been noted by other commentators (Grob, 2013), CAHPS instruments are very much provider-centric; response rates are highly variable; and they are, of course, one-time surveys designed to be administered after discrete episodes of care have concluded. Moreover, most patients with advanced illness are likely to have experienced care in multiple settings, including physician or group practice offices, hospitals, and from home care agencies – in many instances, on multiple occasions – and the individual CAHPS survey instruments are tied to the particular characteristics and attributes of those differing services. Of particular concern in the use of CAHPS for assessing DDDM-based care

is its utility for in-home care, where the survey is very much designed around the Medicare benefit of short-term, post-acute, skilled home care.

A CAHPS-type survey can be very helpful in addressing various dimensions of access to care and, to the extent that specific CAHPS variants address specific services received by patients in DDDM-based programs, overall satisfaction with those particular services. CAHPS also routinely includes a number of questions about: communications between doctors, nurses, and patients; the degree to which patients were consulted on important care decisions; and education on specific issues such as prescription medications. These types of questions could be usefully incorporated into a more comprehensive understanding of patient-provider communications. But for the reasons described above, we believe that any one-time close-ended survey will unavoidably fall short of providing the kind of information about patient satisfaction in care of advanced illness that providers, patient advocates, program managers, payors, and others so urgently require. Those limitations reflect, in part, the relatively limited state of knowledge about such programs, their impact on patients, and the cause-and-effect relationships between program characteristics and methods and those impacts. As we learn more, simpler methods may be more useful. But it is also possible that the very complex, emotionally fraught, and ongoing nature of patient-provider relations as the beating heart of DDDM-based care will never fully lend itself to standardized quantitative measurement.

Next Steps in Measuring Patient Satisfaction in DDDM-Based Care

An appropriate assessment of DDDM programs requires that assessors first come to understand (in a detailed and systematic manner) the multifaceted aspects of how individuals and their family members experience care for

advanced illness. At this point, the range, prevalence and distribution of such key aspects are not well defined. Given the current level of knowledge, it is clear that early research will need to take a more exploratory approach. This will necessitate eliciting information and experiences from patients and family members directly, and may well include eliciting experiences from providers and program staff and administrators as well. In the earliest stages, unstructured and semi-structured interviews are likely to be most appropriate. Such interviews are likely to include a variety of open-ended questions as well as a set of closed-ended ones. Such questions will generate a preponderance of qualitative data and texts. To make sense of these early data, researchers will need to use an interpretive analysis to sort statements into those that have similar meaning. If the interviews were conducted independently, then they can be summed up across individuals. Constructs that are spontaneously mentioned more often can serve as a preliminary measure of salience or importance.

DDDM-based programs that are in their early stages of development may want to use these semi-structured interview protocols as simple quality-improvement tools to assess what is working and what needs improvement in the overall program. At this point, such assessment tools are too preliminary to measure improvement over time or to make comparisons across different types of stakeholders with any level of precision. The tool is also too burdensome to be used to identify patients and families who are not getting the kind of care a DDDM-based model promotes.

The SCAN Foundation, as part of its continuing commitment to advancing the principles of DDDM-based care, is supporting several projects designed to advance the state of the art, and improve the tools available to providers and outside observers alike. In

addition to funding the exploratory work done by Lake Research, the Foundation is also supporting a longitudinal study of approximately 50 patients enrolled in DDDM-based programs over a period of three to six months. The goal of this project is to further elucidate both the characteristics of care that produce greater or lesser patient satisfaction, and to generate some preliminary hypotheses about the relationship between specific patient characteristics and program effectiveness. The Foundation is also working with a firm to examine how frequent, brief, automated telephone inquiries of DDDM program patients might help us better understand how patient well-being and patient satisfaction vary over time and in relationships to underlying health status changes and particular provider interventions. Taken together, these relatively modest projects represent first steps in the evolution of measurement development relative to DDDM programs.

As the assessment and learning process evolves, researchers should assume that the research agenda will move from an exploratory and descriptive phase, to a more comparative phase, and then possibly on to more explanatory and confirmatory phases. As a consequence, researchers should anticipate beginning to develop more structured interviews that contain more closed-ended questions which will in turn generate more quantitative data. These more structured instruments will make it more efficient to collect information for tracking and making comparisons across time, people, and programs. It needs to be recognized, however, that ultimately no detailed and rich description of care can be described by a series of closed-ended questions and that such comparisons and confirmatory analysis is likely to lead to additional questions that need further exploration and therefore more unstructured interviews and open-ended questions.

Conclusions

Americans love to keep score. As care for people with advanced illness comes to constitute a larger and larger share of the entire health services enterprise, the impetus to develop scorecards and ranking systems and dashboards will undoubtedly arise. And such systems can produce some real benefits; patients with advanced illness require timely access to needed services, clean health care facilities, and evidence-based clinical care as much as any other patients. But program managers, individual clinicians, and patients and potential patients and their families will also want to know, in more detail and with more texture, the extent to which patients in specific programs are satisfied with their care, with their relationships with their primary providers, and with the processes by which decisions about their care are made. At the current state of knowledge, highly standardized, quantifiable, inexpensive measures of these critical dimensions of care don't exist. They can't exist, because we don't yet know enough about what really matters to patients and their families, and how their feelings change over the course of an illness and the evolution of the relationships between patients and care givers.

We also know hardly anything about variations in patients' relationships with care providers across different illnesses, regions of the country, or cultures. Patient-provider relationships in advanced illness may vary significantly from West Los Angeles to East Los Angeles to Compton – or from Los Angeles to Vermont – or they may not.

A lot more research is needed, but in the interim (and it may be a long one), those directly involved in DDDM-based care need as much reliable information as they can get. They will need to talk to people, arrange for semi-structured interviews with some number of open-ended questions, undertake content

analyses and other exploratory research. In doing so, they should be reassured that they are not being “unscientific.” To the contrary: they will be engaging in the kinds of early stages of exploratory and qualitative research

that characterize the development of all real science. And in the meantime, they’ll learn a lot, which they will certainly be able to put to good use.

Authors

Bruce Vladeck, Ph.D., is Senior Advisor to Nexera, Inc.

Erin C. Westphal, M.A., is a Program Officer at The SCAN Foundation.

Gery W. Ryan, Ph.D., is Assistant Dean for Academic Affairs, Pardee RAND Graduate School; Senior Behavioral Scientist.

References

Grob, R. (2013). The heart of patient-centered care. *Journal of Health Politics, Policy, and Law*, 38(2), 457-465.

Russell, B.H. & Ryan, G.W. (Eds.) (2010). *Analyzing qualitative data: Systematic approaches*. New York: Sage.

Vladeck, B. & Westphal, E. (2012). Dignity-Driven Decision Making: A compelling strategy for improving care for people with advanced illness. *Health Affairs*, 31(6), 1269-1276.

For more information contact:

The SCAN Foundation

3800 Kilroy Airport Way, Suite 400, Long Beach, CA 90806

www.TheSCANFoundation.org

(888) 569-7226 | info@TheSCANFoundation.org

 Follow us on Twitter  Find us on Facebook

