

Measuring Program Outcomes in Tucson

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"The data available are never what you need; the data you need are never available." This familiar attempt at humor that students in graduate-level statistics courses have heard for decades takes on serious meaning in this era of computerized record keeping. Today, instead of small quantities of data to test this variant of Murphy's Law, we often create massive data bases that answer all kinds of questions—except the ones that are most relevant for program planning.

Nowhere is this more apparent than in research on program outcomes for chronic mental patients. Elaborate studies of patients' hospitalization and rehospitalization rates, employment histories, symptomatology, and levels of functioning answer many administratively relevant questions but frequently fail to probe the more human dimensions of what happens to patients after they have been placed in specific programs (1,2).

In my visits to many programs for the chronic mentally ill throughout the United States, I have often observed major disparities between what the numbers tell and what the programs actually do. Sometimes the numbers are unduly optimistic, to say the least; mea-

sured against the reality of patients' quality of life, they create a fantasy world of good works and hopeful outcomes. Other times the numbers don't say enough; they fail to reflect the caring and human involvement with patients that service providers are capable of exhibiting.

Thus the questions for which answers are readily available in data systems often fall short on two levels. On the clinical level, they simply ask about matters that are not relevant in assessing patients' progress. On the programmatic level, they have limited value for program evaluation, and subsequently for program planning, because they fail to measure whether those programs are contributing to effective patient care.

During a recent visit to Tucson, I was privileged to see the Pueblo Court Apartments, a supervised housing complex for 20 severely disabled individuals, 16 of whom have diagnosed chronic mental illnesses. As I entered the grounds of the landscaped converted motel (there are 19 furnished efficiency units with individual kitchens), a community celebration was in progress. Residents were enjoying cake and ice cream in an atmosphere of warmth and communality that is rare even in populations not handicapped by severe illness.

It is not my intention to provide readers with still another "show and tell" by detailing how many Pueblo Court residents are independently employed, how many of them attend day hospital programs, how many of them have relapsed in the last year, and the like. That is what traditional data systems do so well. My interest is

rather to relate some of the concepts, concerns, and ideals of the Pueblo Court staff: Gordon Packard and Nancy Bissell, co-directors of the parent Primavera Foundation, a nonprofit organization founded in 1983 "to confront and find creative solutions to the problems of homelessness" (3); Sister Celeste Hopkins, the project's director; and Jim and Nancy Santee, the resident managers.

Sister Celeste, in her minutes of the quarterly board meeting of the Primavera Foundation, discusses the importance of devising "useful measurements" of the program's outcomes (4). Beyond this statement of intent, however, all resemblance to traditional program evaluation efforts ceases. The "useful measurements" she describes are qualitative matters that have to do with community and belonging, not with quantifiable data.

In another report, Sister Celeste lists the following kinds of events as being among the "significant signs of progress in community development" at Pueblo Court: increased evidence of courtesy, such as the use of "please" and "thank you"; increased community responsibility during the resident managers' two-week vacation (the residents "raked leaves, swept the sidewalks, took out trash, and *asked* to do the watering and man the gates"); increased expressions of mutual concern; and "beginning to understand that compliance with medication is in their best interest" (5).

Sister Celeste points to other indices of progress as well. The mealtime behavior of residents, for example, "included laughing and talking, mature social interaction." There was a noticeable "increase in affect" at a Christmas party. Residents exchanged gifts and cards voluntarily. They asked about the possibility of forming a baseball team.

Small incremental measures of progress! Yet the visitor to Pueblo Court is left with little question that it is these events that give the community its special warmth and that account in large part for the

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joy of living that residents so obviously exhibit.

It is essential that program evaluation protocols somehow capture and incorporate these kinds of events as they attempt to measure a program's outcomes. The sterile administrative data that frequently pass for program evaluation not only fail to reflect a level of reality that is critical in clinical assessment; they may actually seriously distort the effects of what a program accomplishes.

In the particular case of Pueblo Court, the proximity of a concerned and creative research unit at the Kino Community Hospital department of psychiatry may prove fortuitous. Jose Santiago, M.D., the department's chief, and Michael Berren, Ph.D., its principal psychologist, are currently exploring ways to work with the Primavera Foundation to develop valid and meaningful outcome measures in local programs for chronic mental patients, including those who are homeless. We must hope that other such collaborative efforts that permit service providers and researchers to find a common language will be pursued in other communities as well.

Outcome research for the chronic mentally ill is one of many areas in which it is essential for statisticians to collaborate with hands-on personnel so that they may understand each others' concepts, aims, and vocabularies. It is time to turn this corner in evaluative research.

References

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