The Legacy of SUPPORT

Few clinical research projects have generated as much public interest or as many published articles as SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). The first publication of the study's overall results in 1995 (1) generated front-page coverage in many major newspapers as well as multiple television news stories. At last count, data from SUPPORT have formed the basis for more than 62 published articles, including 9 in Annals of Internal Medicine—the latest of which, by Hamel and colleagues (2), appears in this issue. A forthcoming special supplement of the Journal of the American Geriatrics Society will contain an additional 30 articles based on the SUPPORT data. Innumerable other articles reference the findings of SUPPORT.

What accounts for SUPPORT's impact? In my view, there are four key explanations. First is the study's salience. By attempting to understand and then correct the problems identified among severely ill, hospitalized patients, SUPPORT explored a fundamental human concern. The study consisted of two phases, each conducted at five academic medical centers. Phase I, a descriptive, observational study, involved 4301 patients hospitalized with life-threatening medical conditions so severe that half of the patients were expected to die within 6 months. It produced sobering findings: Physicians didn't seem to know what kind of care their patients wanted, severe pain was unacceptably common, and too many patients died in intensive care units hooked up to machines.

Confronted with these disappointing findings, the investigators resolved to improve them. At that time, the expert consensus was that uncertainty over determining patients' prognoses and inadequate understanding of patients' wishes were the key barriers to improving end-of-life care. Convinced by the expert consensus that targeted interventions would work, the SUPPORT research team designed a second research phase aimed at fixing these problems. Unfortunately, they, and the experts, were wrong.

Phase II of SUPPORT offered the medical team three kinds of special help. First, detailed, validated prognostic models were developed for each patient so that physicians could estimate with precision the likelihood of severe disability or death. Second, a specially trained nurse talked with patients and their families in order to understand their wishes and to communicate them to the physicians and nurses involved. Third, physicians were provided with detailed written instructions about the patient's and family's wishes regarding treatment, including control of pain and use of "heroic" measures such as cardiopulmonary resuscitation. The results of these interventions in an experimental group of 2652 seriously ill patients were compared with those in a similarly sized control group.

When the study code was broken, the investigators were astonished to find that the experimental group did no better than the controls. Specifically, the amount of time spent in the intensive care unit, in a coma, or on a respirator before death did not differ between the two groups. Physicians often were unaware of their patient's preferences for care, but patients and their families didn't raise these issues either. Reports of severe pain were equally (and disturbingly) high in the two groups, and the costs of care were no different. Furthermore, even with hospitalization insurance, nearly a third of the families lost all or most of their savings.

One possible explanation for these disappointing results was that the five prestigious teaching hospitals involved were not representative of the way medicine is generally practiced in the United States. To test this possibility, The Robert Wood Johnson Foundation—SUPPORT's funding agency—commissioned a national survey of 502 families who had recently lost a loved one. About 13% of the deceased persons had died in major medical centers similar to the five SUPPORT hospitals, and about 45% had died in other types of hospitals, generally community hospitals. Results from the SUPPORT hospitals were about the same as those from the community hospitals, and on some key measures—explaining treatment options, giving patients and families the opportunity to influence treatment, and controlling pain—the SUPPORT hospitals did better.

The findings of SUPPORT were thus a blow to the conventional view of improving end-of-life care. The study showed that merely providing information to physicians made no difference to the process...
or outcome of care, and its findings raised fundamental questions about the framing of the problem itself. Like many other landmark studies, SUPPORT challenged the conventional wisdom and challenged the field to interpret the unexpected findings.

The second reason for SUPPORT’s impact was leadership. Outstanding physician scientists directed this complicated, 5-year effort. The principal investigator, William Knaus; the co-investigator, Joanne Lynn; and their colleagues at the five hospitals (chosen in a national competition from among 55 applicants) constituted a dedicated and effective team. This team adhered rigorously to the SUPPORT protocol, yielding a rich trove of physiologic, outcome, and process data on 9105 very sick, hospitalized patients with one of nine common life-threatening diseases.

The SUPPORT team’s outstanding leadership, plus its strict adherence to a well-designed protocol, contributed to the third ingredient for success—methodologic credibility. Despite its disappointing and disturbing results, viewed by some as an indictment of the medical profession, SUPPORT was so credible and so well documented that it was instantly accepted by both professional and lay audiences. Furthermore, because of the richness of its data set and the skill of the multiple collaborators, SUPPORT has continued to generate important new findings about the processes and outcomes of terminal illness.

One such example is the study by Hamel and colleagues (2), which shows that the seriousness of the disease, not the patient’s age, best predicts mortality. Hamel and colleagues examined the records of the 9105 SUPPORT patients to test the extent to which less aggressive care contributes to the higher death rates among elderly persons. They developed a model that adjusted for severity of illness and potential age-related changes in aggressiveness of care. (It is worth noting that although elderly patients in the United States receive less aggressive care than younger patients with similar conditions, their treatment is far more aggressive than that given to older patients in other countries, such as Canada [3]. Age alone was associated with somewhat worse survival at 6 months, but less aggressive care in elderly patients was not a factor. Even the small contribution of age to worse survival was swamped by the roles of acute pathophysiology and diagnosis.

This brings me to what I believe is the final ingredient for SUPPORT’s success—adequate resources. All told, SUPPORT cost more than $29 million, the largest research project ever funded by The Robert Wood Johnson Foundation. (To put this sum into some perspective, a typical research project funded by The Robert Wood Johnson Foundation does not involve patients and costs less than $500,000). Most of the resources were spent during the two data collection phases. But of note, and somewhat atypically, more than $1 million was set aside for data analyses after the study was completed so that the researchers could explore additional implications of SUPPORT’s rich and complex material. As a result, other important findings have emerged in subsequent years, such as the worse outcomes associated with right-heart catheterization (4), the great difficulty in predicting subsequent functional status for seriously ill patients who survive hospitalization (5), the grave financial impact of serious illnesses on patients’ families (6), patient preferences for communication with physicians about end-of-life decisions (7), and an overview of the entire project (8).

In addition, SUPPORT spawned national efforts. Faced with SUPPORT’s findings, The Robert Wood Johnson Foundation embarked on a campaign that would improve the level of dialogue about this issue and reinforce approaches that might make improvements. The result is the Last Acts campaign and a series of grants and programs with three major goals: improving professional education so that physicians, nurses, clergy, and other groups will communicate better with patients about end-of-life issues and provide better high-quality palliative care; changing the institutional environment to eliminate legal, organizational, and financial barriers to better care; and changing public expectations so that patients and their families will be more comfortable discussing these issues with each other and with their care team (9).

That is the story of SUPPORT, an ambitious $29 million multi-year research project that failed to identify how to improve care at the end of life. But out of that failure came a greater understanding of the complexity of care of terminal illness. The study continues to shine a powerful light on these problems, so much so that the health sector—and growing segments of society—are starting to pay attention. Indeed, some 400 organizations have joined the Last Acts campaign to improve care for the dying and their families.

I wish that The Robert Wood Johnson Foundation and other funders could produce more such “negative” studies. To do so will require finding projects that combine salience, leadership, and rigor, and, for our part, we must be prepared to fund them adequately, even through the dissemination phase and regardless of the results.

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References


