Data Challenges for Planning and Evaluating Palliative Care Programs

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Dear Editor:

Anecdotally, hospital administrators and palliative care (PC) leaders say they struggle to get the information they need for planning and evaluating inpatient and ambulatory programs. To determine whether this was the case, we conducted a survey of PC programs.

Methods

A list of 217 valid e-mail addresses of PC clinical leaders was derived from contacts that the authors had from prior projects, such as training programs and prior surveys. Study data were collected using REDCap.¹ Most questions asked about the difficulty of getting various kinds of data or information. We defined difficulty or ease as involving three

characteristics: ease of access to such data; accuracy/trustworthiness of the data/reports; and interpretability. Human subjects review was not required.

Results

Fifty-four responses were received for a 25% response rate. Almost all ($n = 53$, 98.1%) respondents indicated they had an inpatient consultation service. Almost two-thirds ($n = 35$, 64.8%) said they had some form of community-based PC service including one or more of the following: regularly scheduled ambulatory clinic ($n = 27$, 50.0%); home-based services ($n = 23$, 42.6%); and/or telephonic services ($n = 14$, 25.9%). Table 1 shows the percentage of respondents (excluding those who said they had never asked for each kind of

TABLE 1. PERCENTAGE REPORTING THAT GETTING GOOD DATA OR REPORTS ON THESE TOPICS WAS “SOMEWHAT DIFFICULT” OR “VERY DIFFICULT”^a

Domain/information needed (valid N)	% somewhat/ very difficult to get good data or reports ^b
Inpatient PC volumes ($n = 51$)	26.5%
Inpatient PC volume as a percentage of all hospitalizations ($n = 51$)	36.7%
Impact of PC on clinical outcomes ($n = 50$)	57.1%
Length of stay, costs, and revenue for PC-relevant hospitalized patients including those who didn't use PC ($n = 50$)	69.4%
Patterns of hospital use in final months of life for patients with progressive, life-limiting diseases (e.g., percent admitted in final 30 days of life) ($n = 45$)	70.5%
Cost reduction following inpatient PC consultation or use of PCU unit ($n = 48$)	76.6%
Number of patients with progressive, life-limiting diseases who might benefit from ambulatory/community-based PC ($n = 45$)	84.1%
Impact of existing ambulatory/community-based PC program on financial and operational metrics such as hospital admissions, costs, revenues ($n = 33$)	90.6%
Estimates of operational and financial impacts if relevant patients had access to ambulatory/community-based PC ($n = 38$)	94.6%

^aAccessibility of “good data or reports” reflected in the response options: “very difficult: can't get at all;” “somewhat difficult: inconsistent access, or not trustworthy, or difficult to interpret;” “somewhat easy: takes longer than you'd like, or difficult to interpret, but accurate;” “very easy: prompt, accurate, easy to interpret;” and a final option, “I've never asked for data or reports like that.”

^bPercentages reflect the valid N and the exclusion from the denominator of those who said they had never asked for that kind of information.

PC, palliative care; PCU, palliative care unit.

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information) who chose the “very difficult” or “somewhat difficult” responses.

Discussion

With the exception of two data points about inpatient PC volumes, more than half of respondents said they have difficulty getting good data on clinical impact, financial impact, utilization, and costs of PC-relevant patients; number of patients who might benefit from PC; and estimates of possible impact if programs were available.

Despite more than a decade of research² and technical assistance through the Palliative Care Leadership Centers on the methods for assessing the impact of inpatient PC on hospital costs, three-quarters of respondents have difficulty with this task. The very high percentages of respondents saying they had difficulty getting good data or information needed for developing and evaluating community-based palliative care (CBPC) may help to explain the relatively slow adoption of PC in those settings.³ It is difficult to make the clinical or financial case for expanding from inpatient to ambulatory PC without good data on results achieved to date, or the number and characteristics of patients who might benefit from earlier, proactive PC engagement.

Limitations

This survey was completed by only 54 respondents from a nonrandom sample of PC program leaders and staff members, and may not be generalizable. Further research is required to understand the underlying problems that are causing difficulties in accessing the necessary information, and whether similar issues hinder research as well as clinical program planning and evaluation. A companion survey of administrative leaders could highlight the extent to which those individuals feel that absence of data has impacted investment in PC services.

Conclusions

With the spread of alternative payment models, alignment between the clinical and fiscal imperatives for PC has never

been greater. But in order for the associated opportunities to be realized, clinical and administrative leaders need access to trustworthy data describing baseline patterns and probable and actual impacts of PC services.

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