Survey of Provider Perspectives on Patient Assistance Programs

By Roberta Buell, MBA, and Dean Gesme, MD, FACP, FACPE

Sausalito Healthcare Partners; E-Expert Reimbursement Partners, Sausalito, CA; and Minnesota Oncology, US Oncology, Minneapolis, MN

Abstract

Although drug companies proudly market their patient assistance programs (PAPs) for needy individuals, oncologists say navigating these programs too often requires weeks of paperwork, repeated telephone calls, and bureaucratic delays. For years, oncology practices have reported concerns with the time spent on these applications; for those who might qualify for these

programs, the end result is usually delay in appropriate treatment. To measure this difficulty in obtaining assistance, this survey attempted to quantify the costs of applying for PAPs. The survey sample included 100 oncology practices from 32 states. The results confirmed that the current program application process is indeed expensive, time consuming, and often unsuccessful.

Introduction

In 2004, the Medicare Modernization Act¹ changed forever the economics of Medicare outpatient cancer care. These changes have placed much greater responsibility on patients with cancer and their caregivers to find ways of paying for costs related to antineoplastic therapy. These costs can amount to tens of thousands of dollars for the uninsured or underinsured.

The Kaiser Family Foundation, in its National Survey of Households Affected by Cancer,² reported that more than 10% of respondents had borrowed money from relatives; had been unable to pay for basic necessities like food, heat, and housing; or had sought the aid of a charity or public assistance, and an additional 25% of respondents reported that they had expended all or most of their savings (Table 1).

Moreover, the current economic downturn in the United States has exacerbated this situation for patients with cancer. There are now at least 47 million uninsured patients in the United States, along with an estimated 25 million underinsured individuals. This number seems to be continuing to grow.³

To assist patients with unpaid medical costs associated with cancer care, multiple programs, charities, and foundations have been established. Although these programs offer invaluable services to patients with cancer, the application process is often highly fragmented, confusing, time consuming, complicated, and burdensome. This is true whether a patient is seeking assistance for a single drug or for a multidrug treatment regimen. This process seems too often to result in delays in treatment or disruption of care while also engendering financial and emotional strain in both patients and providers.

To document these concerns, we initiated an evaluation of provider perspectives on patient assistance programs (PAPs). This was accomplished through primary market research involving a variety of community oncology practices throughout the United States.

Methods

We surveyed 100 community oncology practices regarding attitudes concerning time spent and imputed costs associated with helping patients navigate the pharmaceutical-related financial assistance application process. We also inquired about difficulties or barriers encountered in the process and asked providers open-ended questions, seeking their suggestions for improving the application process.

A Web-based questionnaire was sent to 875 community practices listed in a proprietary database via e-mail for prompt response (questionnaire provided as Data Supplement, online only). The first 100 respondents were remunerated with modest honoraria for their participation, and only these respondents were included in this analysis.

Results

The desired number of responses was obtained ($N = 100$) within 7 working hours of e-mail distribution of the survey. This rapid response was interpreted by the survey team as demonstrating the high level of concern among survey recipients about PAPs and foundations.

Respondent Demographics

Responses were received from recipients in 32 states, and the responding oncology practices ranged in size from one to 50 full-time physicians, with a mean number of five full-time physicians per practice (not all physicians were medical oncologists). The average number of new patients with cancer seen per practice per year was 1,333; for respondents, this reflected a yearly experience involving more than 130,000 new patients with cancer in the past year. Of the responding practices, 73.2% have been operational for more than 10 years. A vast majority of practices responding were classified as urban or suburban, with only 3.9% of the practices considered rural practices, on the basis of Medicare criteria.

Table 1. Results From the National Survey of Households Affected by Cancer²

Scenario for Patient/Family Member	Answer			
	Yes	No	Don't Know	Refused
You/He/She used up all or most of your/his/her savings	25	73	2	—
You/He/She was/were unable to pay for basic necessities like food, heat, or housing	11	88	—	—
You/He/She borrowed money or got a loan or another mortgage on your/his/her home	7	91	1	—
You/He/She borrowed money from relatives	13	87	—	—
You/He/She was/were contacted by a collection agency	13	85	2	—
You/He/She declared bankruptcy	3	96	1	—
You/He/She sought the aid of a charity or public assistance	11	88	1	—
You/He/She lost your/his/her health insurance	6	93	1	—
You/He/She couldn't buy health insurance because of having cancer	11	86	3	—

Application Completion: Who Is Involved?

In 72.2% of responding practices, the practice preferred to initiate or complete applications rather than have patients or family members do so. Practices reported that only approximately 30% to 40% of programs required that the patient complete all or a portion of the application.

In nearly 25% of the practices surveyed, oncology nurses were the primary individuals responsible for completing the applications, whereas in another 28.6% of practices, applications were completed by another staff member. Thus more than 50% of practices in our survey used highly paid staff members in the patient assistance application process (Fig 1). Respondents in 18.8% of practices stated that PAP application completion constituted more than half of the time at work for staff members involved in the process. In 52.4% of practices surveyed, the application process required 10 to 15 hours per week for those staff members.

Application Completion: Preparation for Application

Of the practices surveyed, 26.2% acquired information about PAPs from a manual list maintained in the office. Pharmaceutical sales representatives provided program information to 47% of the responding practices. Only 15.2% of respondents used the Internet to acquire program information. Of responding practices, 27% reported having standard operating procedures in place related to why, when, where, or how to complete applications for assistance. Before sending a patient to a PAP, 86% of practices did not screen the patient for income level or household size.

Application Completion: Time Spent by Practice and Applicant

Practices estimated that the application completion process took 2 to 5 days from the time therapy was ordered by the clinician until the patient completed his or her portion of the application; the average time was 4.08 days, but this varied

broadly. Time spent by practice staff included an average of 32 minutes to verify insurance and investigate benefits, 62 minutes to locate and evaluate appropriate assistance programs, 44 minutes to call and determine program requirements and possible patient qualification, and 33 minutes to complete the practice portion of the application; it took an average of 36 hours for the patient or caregiver to return his or her portion of the application. After submission of the application, an average of 190 working hours or 7.9 days elapsed before notification of approval or denial of the application by the PAP.

To provide additional support for the survey findings, we interviewed a current vendor for a major pharmaceutical PAP program. This vendor affirmed that 16% of applications received were complete and could be turned around in 2 to 3 working days. Another 84% of initial applications were incomplete, and an average of 8 days was required to obtain the requisite information from the practice and/or patient for final assessment. An additional 8% of applications were rejected twice because of incorrect or incomplete information.

Figure 1. Who completes patient assistance program applications.

Application Contents

We reviewed 39 representative applications used by respondents and noted an average of 57 data elements (range, 29 to 81 elements) required for completion. These 39 applications included 215 unique data elements; approximately 50% of these were common to four or fewer forms.

Results of PAP and Foundation Applications

Responding practices estimated that approximately 10% to 11% of their patients on average were uninsured or underinsured and might benefit from the PAP process. A success rate of 75% or better in obtaining assistance from a PAP or foundation was reported by 62% of the practices surveyed. Only 10.8% of practices reported a success rate of 90% or better.

If no assistance was forthcoming, responding practices reported that 45% of patients were considered for possible referral to a hospital for treatment, averaging almost 12% of the total number of new patients. In 32% of responding practices, these patients were reported as being treated within the practice despite the lack of approved assistance. With 31% of patients, practices pursued other options such as referral to the Department of Veterans Affairs, local charities, or the foundations supported by the practices themselves. This also delays therapy and may narrow therapeutic options.

Satisfaction With PAPs and Foundations

A majority of practices reported being neutral or dissatisfied with PAPs (Fig 2). Representative comments from respondents included the following:

- "It is a stressful time for patients, and I believe in making things as easy for the patients as possible."
- "I think with the cost of cancer treatment these days, it should be easier for offices to help patients, so we can be paid for what we do."
- "We were on hold yesterday for 3 hours and missed the window [to apply]. We had 12 patients to enroll, and all programs were closed."
- "So time consuming."
- "Very tedious process, and we have limited staffing for the amount of time involved; it takes a nurse away from patient care to do the application process."

Suggested Program Changes

One or more suggestions on how to improve the PAP and foundation application process were offered by 83% of respondents. Suggestions included a standardized application process and centralized processing, increased transparency of program income parameters and other requirements, reduced turnaround time to prevent treatment delays and patient anxiety, availability of funding for generic drugs, and inclusion of diagnoses not covered in current programs.

Conclusion

The generosity of the pharmaceutical community in terms of supporting cancer care has been outstanding. Unfortunately,

Figure 2. Satisfaction of practices with patient assistance programs.

drug companies have developed unique and highly variable PAPs that often have complicated programmatic requirements and objectives. These variances have arisen as a result of the many and divergent opinions of internal and external legal counsel, different marketing strategies, and varying abilities to fund internal and external PAPs. Paradoxically, these differences have engendered the current chaotic state of affairs, even though the intention was to ameliorate this very situation.

This survey confirms the existence of numerous correctable obstacles to the efficient and effective use of current PAPs. Using data from the survey respondents, we have formulated a list of features for an ideal, centralized, and efficient PAP process structure.

- Develop an automated application process for oncology practices and hospitals that is sufficiently simple for reasonably trained entry-level staff to competently and accurately assist each patient in a minimal amount of time.
- Create interactive educational tools for providers and patients to ensure simplified compliance with the application process.
- Develop a tool whereby patients, caregivers, and providers can easily gauge eligibility for all PAPs, foundations, and other assistance programs. This tool should be Web based, be easy to use, and require a limited amount of essential information.
- Standardize data elements required by PAPs so that a single application can be completed online or distributed via e-mail or facsimile.
- Develop a Web-based portal with a simplified, automated, and single-process application for use by multiple PAPs.
- Develop an ongoing process to quantify turnaround times for application completion and PAP or foundation response.

Health care reform efforts in the United States will ultimately be required to address the challenge of providing optimal

access to cancer treatment for all Americans. In the interim, strategies to streamline, simplify, and more broadly apply the benefits of PAPs may enhance access to appropriate cancer care while improving efficiency in oncology practices and refocusing the attention of providers away from financial exigencies and back to clinical care.

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Corresponding author: Roberta Buell, MBA, Managing Partner, Sausalito Healthcare Partners, 8 Alexander Ave, Sausalito, CA 94965; e-mail: bbuell@covad.net.

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References

1. Pub L No. 108-173, 117 Stat 2066
2. Kaiser Family Foundation: *USA Today*/Kaiser Family Foundation/Harvard School of Public Health national survey of households affected by cancer. <http://kff.org/kaiserpolls/pomr112006pkg.cfm>
3. Schoen C, Collins SR, Kriss JL, et al: How many are underinsured? Trends among US adults, 2003 and 2007. *Health Aff (Millwood)* 27:w298-w309, 2008

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