Identifying Patients in Financial Need: Cancer Care Providers’ Perceptions of Barriers

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Some eligible patients with financial hardship may not be referred to assistance programs because cancer care providers do not know the full extent of patients’ needs. This article describes barriers cancer care providers face in identifying patients who have financial concerns by using qualitative data from 21 interviews with providers from one Canadian province. Interviews were audio recorded, transcribed verbatim, and analyzed with a thematic approach. Four major themes emerged: no standardized approach existed for assessing needs, family members rather than patients may have better awareness of financial concerns, patients may not be forthcoming about financial concerns, and financial concerns may change over time. Adopting a standardized assessment protocol that routinely screens patients at multiple times during their care, educating patients about out-of-pocket costs, and educating providers to identify and assess financial need may enable more patients to access available financial resources. Although the Canadian and U.S. healthcare systems are different, concerns about out-of-pocket costs may be similar.

At a Glance

- Implementing a standard process and assessment tool that is given to patients at multiple points during their care may address many barriers that cancer care providers face in identifying patients with financial concerns.
- Ongoing professional education will help cancer care providers develop skills to detect patients’ financial concerns.
- Patients and family members should be educated about the potential financial impact of a cancer diagnosis.

Out-of-pocket costs for cancer care can pose substantial financial burden for some patients. Although Canada’s universal public health insurance covers the costs of all medically necessary cancer care provided in hospitals and physicians’ offices, patients may still incur substantial out-of-pocket expenses related to their care. For example, the cost of prescription and over-the-counter drugs and medical supplies provided outside the hospital setting, travel, and wigs and prostheses are not covered. Canadian studies have estimated the costs that patients can accumulate from travel, drugs, and other care-related expenses (Grunfeld et al., 2004; Longo, Deber, Fitch, Williams, & D’Souza, 2007; Mathews, Buehler, & West, 2006) and have shown that financial concerns can create stress and influence treatment choices (Lauzier et al., 2005; Lightfoot et al., 2005; Longo, Fitch, Deber, & Williams, 2006; Mathews, West, & Buehler, 2009). Studies from the United States, United Kingdom, and Australia have reported similar findings (Arozullah et al., 2004; Guidry, Aday, Zhang, & Winn, 1998; Houts et al., 1984; Moore, 1998, 1999; Pearce, Kelly, & Stevens, 2001; Schwartz, Claxton, Martin, & Schmidt, 2009; Wagner & Lacey, 2004).

Several government, institutional, and charitable organizations offer programs to alleviate financial concerns through direct financial subsidies, reduced costs, or in-kind contributions (Lightfoot et al., 2005; Mathews et al., 2006). However, many patients are unaware of these programs and, as a result, are unable to benefit from assistance. For example, a survey in Newfoundland and Labrador, Canada, found that only 25% of patients were aware of the provincial medical travel subsidy program (Mathews et al., 2006). Cancer care providers may therefore, may not refer patients to assistance programs (Wagner & Lacey, 2004).

This article uses qualitative data to describe barriers cancer care providers face in identifying patients who have financial concerns. The authors suggest strategies providers can use to improve assessment of patients’ financial need. This article is based on a larger study that described out-of-pocket costs for cancer care and the impact on patient and provider treatment decisions (see Mathews et al., 2009).

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Methods

After receiving approval from the human investigations committee of Memorial University of Newfoundland and the Newfoundland Cancer Treatment and Research Foundation research management committee, the researchers identified potential participants from the staff list of the provincial cancer care program. Participants were asked to identify other individuals to invite to an interview. Eligibility criteria were active involvement in cancer care in Newfoundland and Labrador and speaking English. Students and trainees were excluded from the study. The goal of the recruitment strategy was to interview individuals who would reflect a variety of opinions and experiences. The final number of interviews was determined by saturation of themes and concepts (i.e., interviewing continued until no new ideas emerged). Consenting participants were interviewed in person or by phone. Each interview lasted up to one hour and was tape-recorded and transcribed verbatim.

Using a semistructured interview guide, the researchers asked each participant about his or her role in the delivery of cancer care, how he or she identified patients’ financial concerns, the types of financial concerns that affect patients’ treatment decisions, and how financial concerns influence treatment. This article focuses on responses to identifying financial concerns.

The researchers used a thematic analysis approach to analyze the transcripts. Data collected were continuously compared to data from previous interviews to identify concepts, categories, clusters, and themes (Berg, 1995; Rowan & Huston, 1997). Two members of the research team independently read each transcript, identified key words, and developed a coding scheme. The researchers coded two interviews together to develop consistent definitions of terminology and to revise and refine the coding template. The researchers resolved disagreements in coding through consensus, creating new themes or integrating ideas within a theme where needed. The remaining transcripts were coded with NVivo 7 software.

Several measures were used to enhance the credibility of the data and analysis. First, the interviewer conducted member checking with the participants by summarizing responses and reporting them back to the participants to verify that their responses had been accurately interpreted (Berg, 1995). By developing the coding template as a team and independently coding and then comparing the first set of interviews, misunderstandings were clarified to ensure the codes were applied consistently (Rowan & Huston, 1997). The researchers kept detailed records of the interviews (transcripts and audiotapes), field notes, and drafts of the coding template (Mays & Pope, 1995). Finally, the researchers provide a substantial description of the context in which the data were collected and analyzed to provide readers with enough detail to place the findings in similar contexts (Rowan & Huston).

Findings

Twenty-five healthcare providers were invited to participate in an interview. Twenty-three individuals agreed; twenty-one (7 men and 14 women) were interviewed, and two were excluded because of scheduling conflicts. Participants included oncologists, surgeons, nurses, pharmacists, dieticians, social workers, and administrators. The participants worked in cancer clinics across Newfoundland and Labrador, 15 worked at the cancer care facility in St. John’s, and the others worked in regional cancer clinics across the province. Participants had from 3–30 years of healthcare experience. Given the small number of cancer care providers in the province, descriptions of participants’ personal characteristics were limited to protect confidentiality. The cancer care providers identified a number of issues that impeded timely and accurate identification of patients’ financial needs.

No Standardized Approach to Assessing Needs

Although many cancer care providers attempted to assess patients’ ability to pay for cancer-related costs, a standardized process or assessment tool was not used at the time of the interviews. As one social worker noted, the practice of discussing financial concerns varied by treating physician.

Often times what happens is, and it varies from physician to physician, but generally speaking, [the physician’s] focus is very much on the diagnosis and treatment options, and unless the patient flags [finances] and says that this is a concern . . . and sometimes I find patients don’t do that. What happens is they wait until they’re referred here [to social work] and then it kind of all comes out.

Specific approaches used to identify and document patients’ financial concerns varied among individual practitioners. Many physicians said that the discussion about financial concerns was often initiated by asking about private drug insurance.

Physician: I have a list of questions that I ask. I always ask if they have a drug plan. That’s very important. I ask what their transportation is and who comes with them.

Interviewer: Is this a formal questionnaire, or is this something you do yourself?

Physician: No, it’s just something that I’ll do and then I’ll dictate it in my notes. Then I’m aware of each patient’s financial status.

Many providers admitted that they relied on nonverbal cues to identify financial concerns.

You get lots of nonverbal queues. You can see the [husband] gripping the side of the chair while the [patient] is leaning into the doctor. You get this information and you’re thinking, “Okay, there’s a problem here,” or you can see the awe come over [his] face. . . .

I don’t think there’s any routine tool. If there is, it’s not very good because we’re having too many people, we’re finding out in retrospect about too many people [who have financial concerns]. . . . If we had a good tool, you wouldn’t have to rely on body language, would you? You wouldn’t have to rely on trying to be a little bit sensitive about writing a prescription.

Family Members May Have More Awareness of Financial Concerns Than Patients

An additional complication is that patients themselves may not be fully aware of financial concerns. Several providers interviewed said that the patient’s spouse (or other family member)
may be responsible for managing finances, so a discussion directed solely at the patient may not be revealing. As an experienced nurse noted, nonverbal cues from family members often trigger her to attempt a conversation with the spouse or family member. The nurse described a patient with breast cancer who had received several rounds of chemotherapy and surgery and was running out of possible treatment options.

So once the physicians say, “This is the type of drug that we have available, do you want to try that?” and [the patient] says, “Yeah” . . . it’s real expensive and you’re looking at about $8,000 a month, and even if you have a copay, you are still going to get hit $2,000–$3,000 a month. [The patient’s] husband has just retired. He has no medical insurance, [and he’s] thinking, “Oh my God, we can’t afford this.”

The nurse added that although many patients are open about their cancer and their concerns, some are not, so routinely asking patients’ families about costs can be problematic in terms of respecting privacy.

The patient is really the person in the driver’s seat. You know we encourage people to bring a family member or friend with them. We can’t have any discussion with the family outside the patient. We can’t target that. Some patients are very secretive.

Patients May Not Be Forthcoming About Financial Concerns

Although some providers ask patients about financial concerns at their initial meeting, other providers interviewed felt that bringing up the topic at the first encounter was very awkward.

It’s intimidating to look up to somebody and ask them right off the bat in one short meeting about finances because people just don’t want that to be answered and to be asked that question.

Providers also said that patients may be too embarrassed or shocked from being diagnosed with cancer to openly discuss financial concerns.

Financial Concerns May Change Over Time

Cancer care providers also stated that the timing of the discussion is important. The care providers noted that many patients mistakenly believe that all costs are covered through Canada’s public health insurance system.

[Patients are] often under the assumption that the government pays for everything. They don’t realize that the government pays the medical piece but the off side of that, they don’t cover the cost of accommodations and meals, so to speak.

Patients begin to realize that some costs, such as travel and lodging, are not covered by the Canadian public health insurance program only when they have incurred expenses. In addition, providers noted that a patient’s financial situation may change over the course of treatment, as illustrated by quotes from two nurses.

I find if you ask them about what type of financial concerns, it kind of turns them off. The general impression is to say, “No, no, that’s not a problem,” and often at the beginning it may not be a problem, partly because they may have some health insurance, but partially because they don’t understand the cost that may be involved.

When [the patient] was apparently diagnosed, her family had a business. They were relatively well off, but this disease and the number of trips back and forth to St. John’s financially ruined the family.

As costs mount over time, patients’ financial concerns likely will increase. Therefore, asking patients about their ability to pay for out-of-pocket costs during the initial visit may not identify patients who will have financial concerns after treatment has started.

Discussion

The current study used qualitative interviews to examine practices used by cancer care providers in one Canadian province to assess patients’ financial needs. The authors found that discussions about patients’ care-related financial concerns were not routine, which supports other studies; for example, research in the United States found that only 15%–16% of patients ever discussed out-of-pocket drug-related costs with their physicians (Alexander, Casalino, & Meltzer, 2003; Piette, Heisler, & Wagner, 2004). In addition, only 35% of physicians reported that they ever discussed drug costs with their patients (Alexander et al.).

Timely and accurate assessment of patient financial status is an important, albeit complex and potentially uncomfortable, task. Implementing a standard process and assessment tool may address many of the barriers faced by cancer care providers. For example, a standard process incorporating financial questions into an intake assessment may ensure that all patients have been screened and reduce providers’ reliance on nonverbal cues (Federman, 2004; Wagner & Lacey, 2004). In a U.S. survey of adults with chronic illnesses, respondents gave the following reasons for not discussing drug costs with their physicians: they had not been asked (66%), they did not think their healthcare providers could help (58%), they were too embarrassed (45%), they did not think the issue was important (45%), insufficient time during the visit (31%), and lack of trust (11%) (Piette et al.). Using standardized questions may ensure that patients are asked about their concerns on a variety of potential costs, including travel and lodging, supplies, wigs and prostheses, and loss of income, as well as drugs. In addition, asking all patients about financial concerns may reduce stigma and embarrassment if patients realize that they have not been
singled out. The current study’s findings suggest that patients should be assessed at multiple points during their care because financial costs and resources may change and patients’ understanding of the financial consequences of their cancer diagnosis may become clearer over time.

The findings also highlighted a need to educate patients about the potential financial impact of a cancer diagnosis and treatment. Many patients mistakenly believe that cancer care is free in Canada and may not be prepared for unanticipated costs related to travel and lodging, prescription drugs, wigs and prosthesis, or home care, which may not be covered through public health insurance programs. Patients also may be unaware of the various government, institutional, or charitable programs that are available to assist them. In Newfoundland and Labrador, efforts are now made to inform patients with cancer and their families about the various resources available to them. For example, a pamphlet on financial costs and assistance programs is included in the “Purple Lupin Kit.” The kit is a package of information about breast cancer routinely sent to newly diagnosed patients in the province by an independent voluntary organization funded by Eastern Health (a regional health authority) and the Canadian Breast Cancer Foundation (Newfoundland and Labrador Purple Lupin Partnership, 2009). Patients also receive information about local assistance programs at each of the cancer clinics.

The current study suggests that a need exists for ongoing professional education for cancer care providers to address barriers to assessing financial need. Training may inform providers about resources available to patients, as well as help them become more sensitive to nonverbal cues and skilled at asking questions about patients’ personal finances. As one of the few healthcare professionals who have regular and ongoing contact with patients, oncology nurses are in a unique position to assess patients and advocate on their behalf (Wagner & Lacey, 2004).

Limitations

In the current study, cancer care providers were interviewed from one Canadian province. Interviews with patients may provide additional insight into financial assessment screening practices and the referral, availability, and suitability of financial assistance programs. In addition, practices and resources available to patients may vary by institution and province, so the current findings may not be transferable to other settings.

Conclusion

The financial costs associated with cancer care may pose substantial burden for some patients. The current study used interviews with cancer care providers to identify several issues that impede the timely and accurate assessment of financial need among patients. Adopting a standardized assessment protocol that routinely screens patients at multiple points during their care, educating patients and families about likely out-of-pocket costs for cancer care, and training healthcare providers to identify and assess financial need may enable patients to access available financial resources.

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