VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

Grateful Patient Fundraising: Stories from Physicians

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many organizations and individuals who helped
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Grateful Patient Fundraising: Stories from Physicians

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Abstract. This symposium includes 12 personal narratives from physicians who have been encouraged by their institutions to solicit donations from patients. This issue also includes three commentaries on these narratives by Stacey A. Tovino, Ceciel Rooker & Alyssa Sutton, and Richard Culbertson. This symposium presents a range of real life examples of how physicians and institutions navigate the ethical issues around fundraising from grateful patients paying particular attention to attempting to establish best practices to minimize any ethical conflicts. Some potential problem areas are also explored around transparency, real or perceived coercion and respect for boundaries.

Keywords. Medical Ethics, Physicians, Conflict of Interest, Fund Raising, Grateful Patients, Narratives

Introduction

With a decline in the growth of government funding for both the clinical and research activities in academic medical centers, philanthropic giving has become remarkably prominent—rivaling or even surpassing government funding (2014). "Grateful patient" fundraising, or the inducing actions associated with philanthropic giving by patients to healthcare institutions, is central to this, with gifts from individuals and foundations totaling $42.12 billion in 2020 (The Giving USA Foundation, 2021, as cited in CCS Fundraising, 2021).

Beyond a necessary evil, grateful patient fundraising has been the focus of ethical scrutiny. Not much imagination is needed to envision what kind of conflicts of interest might arise when institutional funds appear by virtue of a caring relationship between physician and patient. The American Medical Association Council on Ethical and Judicial Affairs issued "Physician Participation in Soliciting Contributions From Patients" in 2004. The report acknowledges that such philanthropic aid is crucial, but it must not interfere with the patient welfare that arises from the physician-patient relationship. Furthermore, it should be done in a way that respects "patient dignity and rights and benefits the community" (American Medical Association, 2004).

In 2017, a summit on grateful patient fundraising convened by Johns Hopkins Medicine Philanthropy Institute, the Johns Hopkins Berman Institute

of Bioethics, and the Association for Healthcare Philanthropy assembled 29 experts from the fields of "bioethics, clinical practice, development, law, patients, philanthropy, psychology, and regulatory compliance" (Collins, Rum, Wheeler, et al., 2018). The group reviewed the entire landscape of grateful patient fundraising ethics and offered a significant number of recommendations on topics ranging from discussions with patients about philanthropy and other clinician-oriented topics, to institutional concerns like confidentiality and privacy. The summit concluded with a discussion about recommended next steps, including conducting research on this topic and disseminating the recommendations in training for clinicians.

Soon after, noting a dearth in the literature on ethical analysis on this topic, Megan Collins, Steven Rum and Jeremy Sugarman, all three part of the 2017 summit, published a review of the empirical data surrounding the topic. They presented evidence that physicians are generally unprepared to discuss philanthropy with their patients and that the most significant effect of solicitation was a negative impact on the physician-patient relationship (Collins, Rum, & Sugarman, 2018). In a study of patients who had given significantly to a single institution, researchers found a vast majority of patients framing it as "gratitude for their care and a desire to advance science and to improve the health and well-being of others." The authors call for the need to better understand potential donor perspectives as well as a curriculum "to teach consensus-based, professional standards to development professionals and to clinicians" (Collins, Rum, & Sugarman, 2018).

Reshma Jagsi, in a response to Collins et al., called for expansion of the agenda. Patient and public perspectives should receive more attention and a greater focus should be put on how "development relates to the possibility of creating differences in the experiences of patients who do and do not have substantial financial means" (Jagsi, 2019).

The legal framework involved with grateful patient fundraising has also been scrutinized (Tovino, 2014a). In "Silence is Golden . . . Except in Healthcare Philanthropy," Stacy Tovino provides a careful analysis of a key regulation within the Health Insurance Portability and Accountability Act of 1996 (2014b). In it, Tovino critiques and proposes corrections to provisions within these "Final Regulations" that increase the scope of the use of protected health information, as well as the ways that this expansion should be communicated with patients.

Tovino has also detailed a set of ethical issues specifically for physicians engaging in grateful patient fundraising (Tovino, 2014b). She exposes the risk of conflicted health care decision making, injustices in health care resource allocation such as treating a donor sooner than another patient who is not a donor, the risk of financial exploitation, and the possibility of breach of privacy. She presents two "catch-22s," showing first that approaches to healthcare philanthropy that reduce the risk of confidentiality breaches seems to raise the greatest risk of distorting the physician-patient relationship and vice versa. The second posits a link between financial exploitation and privacy. She shows that approaches that lessen the risk of financial exploitation seem to raise the most significant privacy concerns and vice versa. In this analysis, Tovino offers corrections to ethical guidelines that help to resolve these catch-22s.

The topic was put before the public in the form of a survey in another recent publication in JAMA (Jagsi et al., 2020). Of 831 patients targeted using a sophisticated algorithm, 513 responded. Approximately half of the respondents thought it was acceptable for physicians to give patient names to hospital fundraising staff after asking the patient's permission. A small percentage even endorsed referring without asking permission. Most respondents (83%) thought physicians talking with their patients about donating could interfere with the patient-physician relationship.

In this issue of *Narrative Inquiry in Bioethics* (NIB), we look at the topic from a different angle and review it in a different key. Narratives from physicians are included in their full detail herein. They are accompanied by commentary from several key thinkers who are (for the most part) not yet part of the academic dialogue.

The Call for Stories

We sought stories from physicians who had experience with grateful patient fundraising at their institutions. We hoped to understand how grateful patient fundraising impacts the lives of these physicians and how it integrates with the rest of their practices.

Authors were asked to consider the following questions:

- What conversations has your institution had with you about "Grateful Patient" fundraising? Have you received any coaching about how to effectively approach donors?
- Has your institution developed guidelines for interacting with patients who offer gifts? What are those guidelines? What do you think of these guidelines?
- Are you comfortable with assisting the development office at your institution with approaching your patients for financial gifts? Why or why not?
- Has the experience affected your job satisfaction? Has it affected your physician-patient relationships? If so, in what way?
- Have any donors expected favors from you (e.g., last-minute appointments, prescriptions that were not clinically indicated, or priority for scarce treatments or vaccines)? Did your institution encourage such favors? Did you feel pressure to accommodate such requests? How did you handle this?
- What would you like to tell the leaders at your institution about its "Grateful Patient" program? What would you like patients to know about "Grateful Patient" programs?

The editors of *Narrative Inquiry in Bioethics* published the Call for Stories in the NIB newsletter and on the NIB website. Additionally, the call was posted on several social media platforms, including LinkedIn, Facebook, and Twitter. It was distributed through the American Society for Bioethics (ASBH), Medical College of Wisconsin (MCW), Center for Bioethics and Humanities at the University of Colorado, and the Health Humanities and Disability Studies list serves. The editors shared the call with the American College of Surgeons General Surgery, AMA Council on Ethical and Judicial Affairs, the Ethics and History of Surgery Communities, the Atrium Health Foundation, and the Saint Louis University School of Medicine faculty. The call was also shared directly with dozens of physician colleagues and friends.

The Narratives

Most of the stories received and included are from those that have had positive experiences with grateful patients, though there are stories in the collection that reveal concerns. In thinking about why we did not receive more submissions related to challenges or negative experiences, we can hypothesize that some might be concerned about their current position, admitting to a negative experience with an employer or group, or having a fundamentally opposed position to involvement in grateful patient solicitations. In the collection of narratives, each author describes their personal journey in thinking through and navigating their own comfort or discomfort in being involved early on with grateful patient fundraising or with being involved in philanthropy on an ongoing basis.

The Commentaries

This symposium includes three commentaries from Stacey A. Tovino, Ceciel Rooker & Alyssa Sutton, and Richard Culbertson. The commentaries draw out themes and lessons learned from the narratives. The commentary authors include experts in bioethics, health law and policy, patient advocacy, development coordination, nonprofit organization, and university administration and finance.

Professor Stacey Tovino serves as the William J. Alley Professor of Law and the Director of the MLS and LLM in Healthcare Law Programs at the University of Oklahoma College of Law. Professor Tovino's teaching and research focus on patient privacy and health information confidentiality, bioethics and the law, mental health law, substance use disorders and the law, and COVID-19 and the law. She has written extensively on the topic of grateful patient fundraising.

Ceciel Rooker is the president and executive director of the International Foundation for

Gastrointestinal Disorders (IFFGD), an international nonprofit working to inform, assist and support people affected by GI disorders. Ms. Rooker has experience in development coordination and has taken part in advocacy efforts in the US, meeting with policymakers on Capitol Hill and providing testimony to the US Food and Drug Administration (FDA) on behalf of the millions of Americans affected by functional gastrointestinal and motility disorders (FGIMDs).

Alyssa Sutton is a Program Coordinator at IFFGD. Ms. Sutton assists the IFFGD president with various projects, particularly in the areas of patient support, education, and advocacy. Ms. Sutton is proud to work with IFFGD and continue to raise awareness for the gastrointestinal community.

Richard Culbertson is Professor and Director of Health Policy Systems Management at the LSU School of Public Health, a Professor of Family Medicine, and Professor of Internal Medicine at LSU Health Sciences Center as well as an Adjunct Professor of Family Medicine at Tulane University. Dr. Culbertson concurrently serves as Head of the Ethics Key Resource for the Louisiana Clinical and Translational Sciences Center. He is formerly the Interim Vice Chancellor for Health Sciences and Associate Dean for Administration and Finance of the Medical School at the University of Wisconsin-Madison; and founding Director for Administration and Finance of the Medical Group at the University of California-San Francisco.

Conclusion

The articles and commentaries provide a broad overview of grateful patient and physician experiences and the ethical challenges, ranging from the individual patient and physician relationship to organizational fundraising dynamics. Although there are no bright lines in either medical or organizational ethics within these narratives, there is guidance on how to approach these complex issues from the bedside to system-wide practices. There is considerable literature on the topic. Physicians and systems would do well to discuss the best approaches that have been developed to protect physicians' overriding obligation to their patients first. At the same time, physicians and the systems in which they work recognize that funding for health care is also a societal imperative in which grateful patient giving is one approach that, if done well, can be beneficial to both patients and the receiving organizations.

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Personal Narratives

Expanding the Definition of Gifts from Grateful Patients

Reshma Jagsi

Acknowledgment. Thank you to the Greenwall Foundation for supporting me while I was working on this subject.

"Ask her, Mama," suggested the daughter of an elderly Latina woman I was seeing in a new patient consultation visit a couple of years after I finished residency training. We had just completed an hour-long discussion of the complex evidence regarding the relative risks and benefits of radiotherapy in her case of early-stage breast cancer, as well as her values and preferences; we had clearly bonded over the course of this brief yet intense experience of shared decision-making, as her daughter indicated by adding: "Mama, she likes to explain things—you should tell her we don't understand what this means." I was surprised by what came next: the patient showed me a document she had been given in the waiting room, asking her to initial if she authorized "contact for development purposes."

A well-intended effort to ensure that patients could control how their information was shared had just backfired. We had just finished a conversation about how daily radiation treatments were going to pose a substantial financial burden to her family. Her daughter would have to take time away from her work cleaning houses, and gas prices were at the time at an all-time high. It did not seem to be an optimal time to discuss what "development" meant. However, after over a decade of reflection and scholarly work that I have led on the subject, I now believe that I failed my patient because I lacked a sufficiently broad conception of development. The broader conception that I propose here is not yet commonly embraced, but I believe that it might actually help resolve some of the most troubling ethical tensions that physicians feel when asked to help with development, a subject that meeting this particular patient helped inspire me to study further over the intervening decade.

Society as a whole stands to benefit when hospitals, especially academic medical centers, gain resources to pursue their clinical, educational, and research missions of service to the community. Donations from grateful patients have long been a means by which hospitals have funded major initiatives; for example, named wings and towers are commonplace at many institutions. In recent years, efforts to raise funds seem to have become more deliberate, and many physicians report a perception of increasing engagement with development professionals to support the philanthropic mission.

Physicians can be particularly effective in facilitating philanthropic donations from grateful patients, but many express concerns about conflicts of obligations and worries about the impact of their involvement on the physician-patient relationship. Indeed, ethicists have articulated reservations about physician participation in encouraging donations from grateful patients out of several concerns. They are apprehensive of conflicts of interest, the inherent asymmetry of power in the physician-patient relationship that can lead to undue influence, concerns relating to privacy and confidentiality, and equity considerations relating to true—or perceived—differences in the services delivered to donors versus others. Coverage by the media and results of a public opinion survey suggest that such concerns resonate with the communities that medical centers serve. Nevertheless, both the 2004 statement from the AMA's Council on Ethical Judicial Affairs on this subject and a more recent statement from a summit of experts expressly permit physicians to discuss philanthropy with their patients in certain circumstances. Given that a third of physicians report having been asked to solicit donations from patients and half of those have done so, further reflection seems sorely needed.

Junior physicians and women appear particularly reluctant to engage in development. As a female physician who was junior myself at the time, I said, "Some patients who get their care here are able to give money to support the hospital so that we can make sure that all patients get the best

possible care and do the research that helps us tell patients what treatments they need. You don't need to worry about that right now, and I promise that this has nothing to do with the care you will receive here."

At the time, I was focused on my patient's lack of financial means. I did not think she could give money. I did not want to make her feel bad about her financial status. I did not want her to worry that her inability to donate would have any influence on my care for her. I wanted to maintain her trust.

But maybe in my attempts to protect against the ethical challenges of such situations, I have been inadvertently robbing my patients of an opportunity to feel empowered by the exercise of altruism. This is the argument that development professionals often emphasize when they encounter physicians who articulate concerns. In interactions over the past decade with my colleagues in development, I have come to appreciate that we must not forget that development benefits not only society as a whole but also the individual patient herself. This makes it difficult to argue that physicians must never engage with their patients on this subject.

Perhaps one way to reconcile these tensions without exerting a chilling effect on the worthy aims of development would be to reconceive development in a way that engages vulnerable populations more directly. Although not every patient is in a position to give financially, many more patients may be able to share than are currently provided with opportunities to do so. Simply sharing a story could help development officers promote a hospital's needs or inform their understanding of the community's needs. Such contributions, albeit non-monetary, are important contributions to the philanthropic mission nevertheless. Recognizing them as such could help to address equity concerns and engage more patients in an altruistic endeavor to the benefit of themselves and others in their community. The opportunity to partner with development professionals simply to share one's story and perspective—an effort that requires little time, which is important because certain patients may not be able to spare time any more than they can spare money—may still constitute an opportunity to make a unique contribution.

Therefore, I believe the development community should move to abandon the now common practice of wealth screening—sometimes based on public records even before patients ever have a clinical encounter. (This is allowable based on a 2013 revision of the HIPAA Privacy Rule.) They should also abandon training physicians to identify individuals with substantial financial means for referral. Although such practices intend to avoid bothering those who lack the means to donate money (preventing awkward conversations precisely like the one I had with my patient), they seem distasteful to many physicians, are opposed by most members of the public, and act contrary to our shared goals of serving all patients equitably. Abandoning these practices would make the benefits of altruism available to all and promote our institutions' worthy missions. Instead of focusing on those with substantial financial means, development officers should be encouraged to build relationships with all patients who wish to help the institution serve its mission—including those who cannot donate money but are willing to help in other ways. This includes the brief but meaningful effort to share their stories and their unique perspectives of what the community actually needs from the institution to help guide fundraising efforts that could better serve the whole community.

What do I now wish I had said to my patient? How might I have reconciled what seemed like conflicting obligations to help both her and my institution? I believe I was right to hold paramount my duty to her, and I was right in recognizing that this was not a discussion that would have been appropriate in the context of her initial consultation.

That said, I now believe that I should have considered the potential benefits that she might have gained if I had offered her a chance to contribute later on. If I had recognized then as I do now that everyone can contribute something, I might have said: "Right now, I think our main priority is on getting you the radiation therapy you need. Let's focus on that now, and we can talk about this handout at some later time if you'd like when we've got the plan for care working well." When that conversation came around, I might have begun by asking her for her perspective, and then I might have

explained, "Some patients who get their care here are able to give money to support the hospital, and it helps everyone. Other patients who can't give money can help in other ways, by giving their time or sharing their stories to help encourage those who can donate money to see how important it is for them to help. Sometimes patients can, by sharing their own experiences, help donors understand the needs that exist in the community—needs that the donors might not otherwise recognize. Doing something like that can be an important part of the healing process, and many patients feel better knowing that they have done something to help others. If that sounds like something you'd like to pursue after treatment, I can give you the information for our volunteer and development offices if you'd like to look into those opportunities further. Development is just a fancy word for helping us raise funds to do the good things we do here."

The opportunity to share—be it money, time, or a unique perspective—is something I hope to be able to offer to all of my patients in the future, now that I appreciate that donation is not a privilege that can only be exercised by the wealthy. I hope that my colleagues in development will provide physicians who share my worries about equity a way to make more general referrals of all patients who wish to give, regardless of means, in an attempt to find a more ethically satisfying way to support the patients and community we all serve.

Bidding for a Grateful Patient

Joel S. Perlmutter

Patients and families frequently want to help support my research efforts, particularly when there is potential for discoveries that may translate to more effective clinical treatments. Support includes potential participation in research studies as well as financial support. Such donor financial support has huge advantages for me as an investigator. These funds can help support preliminary studies to determine whether some new research direction will be productive. These preliminary data form the critical base for a larger application to the National Institutes of Health. Almost all such submissions require such data to be competitive. Thus, these types of donations provide the "seed funds" to pursue new, innovative ideas.

Given that background, one can see why the University Development Office wants to encourage interactions between clinician-scientists and potential patient donors. Of course, as a scientist, this aligns with my interests. Yet, as a clinician, I am somewhat reluctant to initiate these discussions with patients or families since I do not want that to intrude on the patient-physician relationship. In particular, I do not want to have any sense that I am coercing someone who depends upon me for care, nor do I want the patient to feel an obligation. Most particularly, I also want to avoid "reciprocity" in which the patient, their family, or my office feels an obligation to ask for or provide different care. Note that I state "different care" since I aim to provide all of my patients and families with "special and personalized care." Thus, if a patient and family raises the question of support, I refer them to the development office.

Well, I have not always followed this rule. Let me tell you a story of a different interaction that I still question. One Wednesday evening when finishing with the last patient of the day—it was about 8:30 pm—I had just completed the evaluation and discussion of treatment options with a man that I had treated for several years. His adult son, who had accompanied him on this visit, asked me about what was going on in my lab. I knew that it was late, but quite frankly, I rather enjoy talking about my work, so I did. I told them about a new drug that had been developed at Washington University by one of my colleagues, Laura Dugan, and we had just completed a study demonstrating that this drug can recover damage in the brain produced by a neurotoxin that causes an animal model of parkinsonism. Quite frankly, this was rather amazing since the treatment of Parkinson disease has only included symptomatic treatment and nothing slowed the relentless progression. The son then asked me about the next steps, and I explained that

I wanted to develop a measure of the action of this drug in the brain so that I could rationally know that if I extended this work to people with Parkinson disease, I could hit the target in the brain and with the appropriate dose. That evening he asked if I had time to meet with him on Friday morning before he left St. Louis to return home. I said fine, not really knowing anything about him or his family. I had assumed that perhaps he would donate $100 or so to help. But I could not pass up a chance to talk more about my work so we planned on a one hour meeting in two days.

So, two days later the son walked into my research office, sat on the other side of my desk and he asked me some rather poignant questions. What were my goals of the research? How long would it take to collect enough preliminary data to submit a viable federal grant application? What was the value of the new methods that I wanted to develop if the drug that we had been testing failed to work in humans? Finally, how much money would this cost? I was not really prepared for that last question so I turned to my computer, pulled up a spreadsheet, quickly formulated a budget and said "about a million dollars." To which he responded, "fine." Needless to say, I was more than a bit surprised but I managed to stay in my chair. At that point, I suggested that he talk with the Development Office people to work out the details. The funds were obtained, the work completed and a successful grant application submitted to the National Institutes of Health.

So, what is the ethical issue? I am coming to that now. At some later point, I recommended that this person consider deep brain stimulation (DBS) to treat his condition and referred him to our DBS group, which includes movement disorders neurologists and neurosurgeons. I made no mention to anyone of the donation and asked for no "different" treatment since I believe we provide everyone with "special" treatment. The surgery would require staying in St. Louis for immediate post-op time and then frequent visits for adjustments of the stimulators to optimize the benefit. I had talked to the family about this and since the patient lived in Florida, I recommended that he also consider having surgery at an outstanding DBS center there since that would be more convenient for them. He had the surgery done in Florida and I saw him the day after surgery since I had gone to the medical center as a visiting professor on that day. The bottom line is that he did well and that Florida university now has a Neurology department named for this generous donor.

How do I feel about this and how does my development office feel? Interestingly, I feel totally fine. I provided the care that I always like to provide. The patient and family supported my preliminary data that helped us move forward in our research project. I sent him to another outstanding clinical facility; he obtained excellent care; and that university benefited tremendously from their very generous support. I never heard any disparaging comments from anyone at Washington University. I still believe that I handled this correctly, but I also must admit there is some little whispering in the back of my head about whether I should have done something differently. But, I know the next time that I would take the same actions.

Reciprocity could have led to trying to offer "special treatment" when they were pursuing DBS at Washington University, but in my mind "special" is not necessarily better. I wanted them to have the same outstanding care we provide to all of our patients. I also wanted them to pursue an avenue that would be most reasonable for them, regardless of their expectations. That is why I referred them to a center in Florida. If I had felt an obligation from the gift, I may have tilted to extending a red carpet, but that does not necessarily lead to better outcomes. I was fortunate not to have any pressure exerted on me by anyone at Washington University. Pursuing donors and seeking and obtaining gifts will always raise the potential for reciprocity. The challenge for me is to navigate these deep waters and avoid bidding for more donations.

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Chapter of the APDA, Paula and Rodger Riney Fund, Jo Oertli Fund, Huntington Disease Society of America, Murphy Fund, and CHDI.

For Ethical Fundraising from Patients, Respect them as Partners

Brendan D. Curti

For over 25 years, grateful patient donors and their families have financed breakthroughs in cancer immunotherapy at Providence's Earle A. Chiles Research Institute (EACRI) in Portland, Oregon. Patients and their families have given nearly $200 million to our community hospital-based program—and, while our researchers compete successfully for NIH and other public funding, grateful patient giving currently makes up nearly 70% of our budget.

In my 20 years with EACRI, many of my own patients have become financial supporters of our research and volunteer to assist fellow patients in their cancer journey. One of them has contributed several hundred thousand dollars, spoken at events, and provided valuable advice as a member of one of Providence's foundations, which works to connect the community to our research team.

Never during my tenure with EACRI have I experienced medical ethical concerns about a grateful patient donor relationship. Foundation staff members have never asked me to invite a patient to an event or make any other fundraising "move" as part of a clinical visit, and none of my patients have suggested I give them access to a different treatment in exchange for a financial contribution. In fact, engaging patients in supporting our research has been remarkably uncomplicated and deeply rewarding, both professionally and personally.

This engagement is not contrived. It doesn't arise from any grateful patient fundraising training, which I've not received. It flows naturally out of my duty (and pleasure) to educate my patients about their disease and treatments, including research options—and out of an understanding shared by everyone in our institute that anyone can contribute to ending cancer.

During clinical visits with my patients, my only role is to help them through what is probably the most difficult situation in their lives. But patients are naturally curious about cancer and its treatment, and, as a physician, I am both healer and teacher. Part of answering my patients' questions is to tell them that we have a research program and that I spend most of my time doing research, along with a large number of PhD scientists. I never volunteer that they can contribute financially or that we have a foundation; if they do ask how we pay for our research, I tell them the truth, that it's powered mostly by private philanthropy (including my own small gifts), peer-reviewed grants from places like the National Institutes of Health, American Cancer Society, the Susan B. Komen organization and pharmaceutical companies. If they ask how they can support the research, I let them know that there are brochures in the lobby or ask if they would like us to have a member of our foundation call them. (Our foundation has kindly provided us with stickers with its phone number on them for the backs of our cell phones!)

If a patient—any patient, expresses a strong interest in learning more about our research, I ask them if they would like to tour our laboratories. Typically, the foundation handles scheduling without first investigating the patient's giving capacity. I participate in tours whenever I can, again focusing on education. I talk about the history of the institute, how it came to be that we have world-class immunotherapy here, and some of the research underway. Frequently I tell the story of OX40, how it was derived from research spurred by a patient's challenging question and received support from private donors before it won NIH funding and developed into a company founded by one of our institute members. If the patient says, "We didn't know that cancer research was such an important part of the mission here to improve care for patients. How do we support it?" I smile and point to the foundation representative and she takes it from there.

To maintain my role as healer and teacher, I never participate in any solicitations or discussions

with donors about potential gifts—though I may participate in reporting out to donors the impact of their giving.

I do attend fundraising events with donors, some of whom are my patients. But I don't issue the appeal to them; I raise my own paddle alongside them. And this brings me to my second point; the ease and simplicity of our relationships with grateful patient donors flow from an organizational belief that curing cancer is a community endeavor to which anyone can contribute.

Compared to many others, EACRI is not a large cancer research program. We have been effective because we have been able to integrate clinical care, clinical research and basic research more closely than is possible in most places. Everyone is on the same team: physicians, patients, families, nurses, scheduling secretaries, volunteers, PhD scientists, and data managers. One of our project administrators captured this well: "The environment here at the EACRI is a highly collaborative one, where each person's contributions are valued and appreciated regardless of title or tenure."

Grateful patient donors are respected as part of the team because they provide essential funding that gives the rest of us the time and flexibility needed to sustain our bench-to-bedside collaboration. We could not do our work without them—and everyone at EACRI recognizes that. We also respect the many non-monetary ways our patients contribute by participating in clinical trials, serving as volunteer educators and advocates, and humbling us with questions that sometimes lead to important discoveries.

In exploring this culture of respect, I spoke with EACRI's founder, Walter J. Urba, Director of Cancer Research, EACRI and Physician Director of Research, Providence Health & Services—Oregon Region. According to Dr. Urba, a strong partnership with patients and the community has existed from the institute's beginning, when two philanthropists, Earle Chiles and Robert Franz, joined administrative leaders from Providence in recruiting him to lead it. "They convinced me that they would help bring the people we needed here," he said. "And they kept their word and supported us throughout their lifetimes and through their estates."

In my time at EACRI I have observed Dr. Urba deliberately cultivate respect for grateful patients among the institute's physicians and researchers. Recruitment meetings frequently include donors. New recruits meet and learn the role of the foundation team as part of their orientation. Physicians and researchers present their work at meetings of the institute's volunteer leadership cabinet and philanthropic dollars are spread among researchers, so we all know where part of our salaries or lab support comes from.

Dr. Urba is clear with institute physicians that he never wants fundraising to come between them and their patients. He leads by example and as a mentor has helped me to appreciate that fundraising opportunities can be a natural outgrowth of the physician/patient relationship. He tells new members of the institute that he once had to explain to a patient that he could only see her on Wednesdays because he did research the rest of the week. "She said 'Gee, our family supports research. Tell me more,'" he recounted to me. "I didn't know who she was. It was just the friendly give-and-take of a relationship."

Grateful Patient Fundraising: Gratitude Matters

Leslie Matthews and Leah Murray

Editor's note: This narrative was written by Dr. Leslie Matthews MD, MBA, MS and his Philanthropy colleague, Leah Murray, MHA.

Leslie Matthews: A Collaborative Approach to Grateful Patient Fundraising

The concept of fundraising initiatives within a healthcare setting traditionally involves patient-focused fundraising. Most often, this is incredibly uncomfortable for providers. As an

orthopedic surgeon and Chief of Orthopedics for MedStar Health, I was of the same thought. For my colleagues and me, the idea of talking to a patient about a philanthropic investment felt like a breach of the doctor-patient relationship, unethical, and a HIPAA violation. As a physician, I did not want to be in a situation where I needed to ask a patient for money. However, I've been introduced to a new concept and approach, which is in place at MedStar Health, that is much more comfortable for the provider and removes the typical ethical objections physicians voice in partnering with philanthropy.

Our Philanthropy approach at MedStar Health focuses its fundraising efforts around the concept of facilitating patient gratitude and building a culture of gratitude among caregivers and employees across the organization. The methods are rooted in the definition of philanthropy as "The love of humankind." Conversations with providers at all levels are centered on this concept through a series of education and relationship-building efforts held with the philanthropy team members. Understanding that grateful patients, their families, and community members may have a desire to express gratitude by helping other patients like them through philanthropy is key. Education and conversations with providers and staff are centered around gratitude—how gratitude is personal and meaningful to patients and their families, how to recognize and "accept" those expressions of gratitude and then when and how it's appropriate to connect them with a colleague in philanthropy. Providers are not asked or expected to offer differing levels of care nor to ask patients for donations. They are trained to respond to expressions of gratitude with warm responses like, "It's my pleasure" or "Thank you for your trust," as opposed to the all too common "No problem" or "I'm just doing my job." Additionally, providers are trained to refer grateful patients who express a desire to become involved in giving back to philanthropy colleagues for follow-up. Providers are encouraged to think of their philanthropy colleagues as an extension of the care team, where our philanthropy professionals can triage their gratitude and match them to the most appropriate opportunity.

When philanthropy team members invite grateful patients and their families to become more involved with the organization, they recognize that this is a deeply personal and meaningful experience that will take shape in a variety of forms based on the individual—volunteering, sharing a story, or making a philanthropic investment. One of the conversations that takes place with providers and associates about gratitude is the meaning behind these expressions. Most often, providers assume that the care they provide is routine and "just part of their job," but to the patient and their family, it may feel extraordinary. Imagine a double-pan balance scale—an act of kindness from the provider or staff member (e.g., making a gesture to ensure a patient's comfort or engaging in a friendly conversation to ease the anxiety during an appointment) can "tip" the scale for the patient. It's common for individuals to want to do something in order to find equilibrium. In our own lives, we may experience the same. When a neighbor, friend, or family member does something kind for us that's unexpected, unearned or not requested, most often, we want to do something in return to express our gratitude. Patients and their families experience the same emotion.

The conversations that take place between philanthropy professionals and our care teams are rooted in gratitude with ongoing training to recognize sincere, heartfelt gratitude, its meaning to the individual, and the importance of their response, as well as *when* and *how* to refer to the philanthropy office.

Leslie Matthews: Interacting with Grateful Individuals

Our philanthropy team at MedStar Health makes every effort to remove our providers from the "ask" when patients express gratitude and a desire to give back. We educate providers to first accept the gratitude with a warm response. This is a crucial step in the process and one that can impact the patient experience. For example, a patient may express a sentiment like "Thank you so much for all that you've done for me" or even "You've saved my life, I can't thank you enough." If not responded to

warmly by the provider, then the depth of emotion being expressed is not acknowledged. I'm reminded of the quote by William Arthur Ward "Feeling gratitude and not expressing it is like wrapping a gift and not opening it." Our philanthropy team suggests changing the response to "Thank you for your trust" or "That means the world to me, I will share that with my team," etc. These interactions create positive emotions, where patients feel heard and cared for by their provider. However, in some instances, that expression isn't enough to "find equilibrium," and patients feel they want to go beyond a kind expression to display their gratitude.

After warmly accepting an expression, the training continues to coach our providers to continue the conversation by saying something like, "we have a number of projects ongoing that are very important to me. If you would like to learn more about them and how you might help, then I'm happy to connect you with my colleague in Philanthropy." This system does not require or mandate any connections to grateful patients. Our Philanthropy team feels that introductions and an invitation to learn more about a physician's work should be organic and part of a natural conversation. In our experience, when physicians offer a patient or their family member to learn more about their work and then provide only their name to the philanthropy office for follow-up, then the physician is removed from the conversation. It's our goal that the physician should only remain focused on care delivery and not be involved in any philanthropic or gift conversations.

Our philanthropy team is deeply invested in this approach through continued education and engagement with providers about gratitude to the extent of creating a MedStar Philanthropy Academy. The Philanthropy Academy, led by my co-author Leah Murray the Director of Philanthropy Education at MedStar Health, is a central resource to create and provide materials and training for care teams across the system as well as offer ongoing support to the broader philanthropy team. The goal is for the academy to create a centralized approach, where the team engages and educates with providers that's consistent with the goals and philosophy of the Philanthropy team.

Leslie Matthews: Working with the "Development" Office

The Philanthropy team is intentional about shifting language away from the traditional "development" and "fundraising" language, which is familiar to many of us in healthcare. Our philanthropy team should not be seen as prying dollars out of the reluctant to support our own agendas, but rather seen as facilitators of the love of humankind. When Philanthropy is part of everyone's title in the department, the word becomes part of our "ethos" and a value to embody as we implement our work. As a result, working with the philanthropy office is not intrusive but rather a collaboration between the two parties—physician and philanthropy professional. I think of the relationship with philanthropy as I would the rest of the care team. As a physician, I don't perform tasks like physical therapy, blood draws and vitals, fill medications or navigate the billing process, etc. I rely on the experts in those areas to perform those tasks with the same care and attention I give to their orthopedic needs. I think of the relationship with philanthropy similarly. I'm not the expert in navigating a philanthropic investment, so I refer to the philanthropy professionals who dedicate their careers to those tasks.

In order to create a collaborative relationship, philanthropy team members should build trusting relationships with the clinical teams and physicians. The interactions most often occur through regular meetings with the department in a staff meeting with brief time on an agenda or through one-on-one conversations. The goal of those conversations is to build trust and rapport, maintain transparency, continue education on gratitude, keep gratitude top of mind for the care team, discuss recent gratitude expressions for follow-up and provide updates on philanthropic activity.

Leah Murray: Job Satisfaction and the Patient Experience

Aside from discussing expressions of gratitude from patients and their families, our philanthropy office has a secondary goal to build a culture of gratitude among our care teams and across the organization.

Interactions may also be around sharing recent studies on gratitude and its impact on patient satisfaction, employee satisfaction, and caregiver burnout. It is our goal that all communications from the philanthropy department are rooted in gratitude and encourage it to be expressed and received by everyone—including staff, physicians, nurses, administration, etc. Gratitude impacts everyone.

Numerous studies and our own experience show unequivocally that a gratitude culture will enhance provider well-being and patient satisfaction. The philanthropy team offers tools and resources for the care teams to express gratitude to one another through gratitude boards, journals, kudos notepads, thank you notes, and by encouraging "gratitude moments" in meetings or huddles. Our organization recognizes that gratitude is not only a significant and personal emotion for our patients and their families but is just as meaningful to our employees as well.

Leslie Matthews: All Patients Receive the Same Level of Care

It is not the expectation for anyone to offer differing levels of care because that would be highly unethical and against our mission as care providers. The tagline of MedStar Health is "It's how we treat people," and every patient should be treated with the same level of care, courtesy, and respect. If a philanthropic partner or volunteer makes a request for services, we can offer to help or be of assistance when it's feasible to do so and without having any impact or interruption on the care of someone else. It's our opinion that philanthropy should not encourage, request, or expect any provider to do so at the expense of patients of lesser means nor as a means to recruit donors. Our philanthropy team understands that sometimes accommodations cannot be made and should not pressure physicians and providers to do so.

Leslie Matthews & Leah Murray: The Message

The message best conveyed to system leadership as well as providers and patients is that gratitude is significant and meaningful to everyone. All expressions of gratitude have equal weight but will materialize in a way that is unique and meaningful to each individual, whether donating time, talent, or treasure. A philanthropy program rooted in facilitating emotions of gratitude in order to help individuals express their love of humankind, regardless of financial means, presents to operate in a way that removes much of the uncomfortable aspects of traditional healthcare fundraising. Since shifting our philanthropy work to focus on gratitude, we have achieved record results in philanthropic support for our system and continue to see enhanced benefits to our patients, their families and our providers at all levels.

Grateful Giving in Medicine: A Personal Story

Ahmet Hoke

Author's note. This story, while true, draws details from several of my patients into a composite, to safeguard the patient's identity and privacy.

Mrs. Jones, a 63-year-old executive, came to my office in a prominent academic medical center in 2010 with nerve pain. Prior to her arrival, I had been alerted by development staff that she was an avid philanthropist and, though she had not yet given to our institution, she had the financial capacity to do so. Over the ensuing year, my interactions with Mrs. Jones followed two separate but parallel paths: I served as her doctor, treating her clinically for her condition, and, guided by my development officer, I discussed with her my research vision, current focus, priorities, and funding gaps. For the latter conversations, my development officer carefully shepherded a multi-year process that resulted in successive gifts for my research: a six-figure commitment in 2011; another similarly-sized gift in 2014; and, in 2019,

an eight-figure commitment. Her generous support continues to enable the work I do to better understand peripheral neuropathy and nerve regeneration and develop new, more effective therapies.

I feel fortunate to work for a medical center that performs grateful patient fundraising (GPFR) in a professional, ethically sound way, a way that respects patients, physicians, and the relationship between them, allowing the physician-patient relationship to remain focused first and foremost on the patient's health and well-being.

Mrs. Jones was one of the first patients to open my eyes to the fact that philanthropy can benefit not only my research, my institution, and me professionally, but also the donor. I entered the realm of GPFR as a complete novice and through an unusual door: I accepted an invitation from my institution's Vice President for Development and his physician-scientist partner to participate in a research study examining development practices, specifically, methods of engaging physicians in GPFR. I enrolled in a unique randomized controlled trial (RCT) that compared three practical methods used by development staff to educate clinicians like myself about GPFR: a web-based module, a group lecture, and one-on-one coaching. Study participants received training in one of these three ways for six months; results were published in 2010 in *Academic Medicine*.

As one of the physicians randomized to the study's "coaching" arm, I was trained by our Vice President for Development who was employed by my institution and trained in the protocol. Training covered various topics ranging from background on philanthropy (e.g., why patients give), to how development works (e.g., how development staff work with physicians), to ethical considerations and how to manage them.

Philanthropy and fundraising had occupied no space whatsoever in my medical education or specialty training. Admittedly, I started the coaching a bit skeptical. I had reservations about how GPFR might work for my patients and me but I chose to enter the study with an open mind. Among the many details I learned, there are two general points I would like to convey: First, when GPFR is practiced well, it does a service to both donor and recipient—be the latter a physician, institution, field of medicine, scientific community, future patients, or all of these. Typically, donors through the GPFR process actually have or had the disease that we (their physicians) treat and study. If their experience of care has been positive, they often want to "give back" out of gratitude. Mrs. Jones, for example, was appreciative of the care I gave her; my sense is that she has felt grateful both for the quality of care and attention she has received, and also for the genuine personal concern I have consistently shown her (as I do all of my patients). She wanted a way to say "thank you," and making a financial gift enabled her to do so. I directly witnessed the personal fulfillment she gained from this philanthropic act.

A second overarching concept I took away from the RCT was that there is indeed a professional way—a way that is sound, boundary-preserving, and ethical—to practice GPFR. When thus performed, GPFR does not compromise the physician-patient relationship and can actually strengthen it.

GPFR is not a "seat of the pants," mysterious, or "intuitive" process, unfolding at the discretion of each development officer. Rather, it follows a regular progression. The coaching I received—now a "curriculum" that my institution provides to all—informed me about the stages of a gift cycle, namely, identification, engagement and cultivation, solicitation, and stewardship.

With Mrs. Jones, the process has played out as follows: She was first identified by development, via publicly available information, as a patient with the financial capacity and potential inclination to make a gift. My development officer, whom I'll call Mary, used various open-access data to generate a picture of this person, her background and interests, what she cares about, her giving history, and her possible further philanthropy.

At the end of one of my clinical appointments, Mrs. Jones indicated that she had an interest in supporting my research. My coach in the RCT instructed me that I, myself, did not need to raise the topic of philanthropy with patients, but should instead watch for signs of interest or inquiry from Mrs. Jones and, if she expressed curiosity about my research, to ask her if I could put my development officer in touch with her. At this juncture, I asked Mrs. Jones if I could pass along her contact

information to my development officer, and she was amenable. At this point, I stepped back and Mary made the initial GPFR-related contact, scheduled meetings for that purpose, and moved the process along.

Over many years now, Mary and I have worked together to engage with Mrs. Jones which, in her case, we do primarily through written research updates and periodic in-person meetings. These GPFR-related meetings are always scheduled (a) separately from clinical visits, and (b) at a time that is sensitive to her health, well-being, and comfort, for example, not during active treatment phases. At the appropriate time, Mary has assumed all responsibility for soliciting so that the request for money would in no way impact my rapport with my patient. Following each of Mrs. Jones' gifts, Mary has worked closely with me to communicate, in various ways, my gratitude and the impact of her gift. With this division of tasks, I have been able to maintain a strong physician-patient relationship with Mrs. Jones while, separately, Mary has built and deepened, through ongoing stewardship, a strong fundraiser-donor relationship with her.

Like many physicians, I initially had concerns about the ethics of asking patients for contributions to a doctor or institution that treats them. I worried that this might violate my commitment as physician to my patient, or that the introduction of a possible financial interaction might jeopardize our clinical relationship. Most importantly, I wanted assurance that raising the concept of giving would not negatively impact the patient in any way. As a physician at the outset of my career, I took what I consider a sacred oath to "do no harm." Harm comes in many forms, including emotional damages such as feeling valued for one's wealth rather than for one's self as a person, feeling pressured, or losing trust in one's physician or institution—all potential ethical violations of GPFR if wrongly practiced.

My institution's development team was concerned, as well, about the potential risks inherent in GPFR and the lack of ethical standards. To address this issue directly, in 2016 they hosted a Summit on the Ethics of GPFR, which engaged national representatives of the key stakeholder and informant perspectives. The 29 participants were physicians, grateful patient donors, academic administrators, a leader in the American Medical Association, development officers, and faculty in psychology, law, and medical ethics from various institutions across the country.

The conveners of the Summit—leaders of our institution's development office and bioethics institute—viewed the immersive, day-and-a-half gathering not as a policy-setting forum nor as a group empowered to outline definitive standards for ethical practice. Their intention was, for the first time, to (1) systematically name all of the significant potential ethical issues that might arise in the practice of GPFR, and (2) begin to develop answers to them from a broad range of perspectives. The Summit's primary goal, through work extending several months beyond the Summit, was to develop a set of draft recommendations that could be discussed in relevant professional communities—medical, legal, ethical, development—honed, and adapted as appropriate for use within medical institutions. These recommendations have been published in *Academic Medicine* and *JAMA*.

Returning to my own story, I have been fortunate to have several other affluent patients join Mrs. Jones as supporters of my research. Mary continues to work with me, cultivating and stewarding the donor relationships, and making the requests. She always takes the lead in initiating the first discussion with patients about their potential interest in supporting my research, and she ensures my comfort with the process, for example, my desire that we not create unrealistic expectations of what might result from a gift.

I would like to close with a note of realism and a note of gratitude (my own). We live in a country that has vast financial disparities and also tremendous generosity. Individuals in the United States, collectively, give billions of dollars each year to the country's medical centers. The significance and impact of their giving cannot be underestimated; they make a huge difference for institutions, medical knowledge, and future patients.

Philanthropists know that they make a difference in our society. Our invitations to them, extended by development staff, to engage in the GPFR conversation rarely if ever (in my observation) come as a

surprise. Most, I believe, sincerely want to help, to make a difference.

Lastly, I personally am very grateful to the patients who have given so generously to support my research, and to the development staff who have carried the weight of the GPFR process, allowing me to focus on my patients' care and my research. My development partners help my patients connect with the world of medicine in a different way than they experience by simply being a patient, and I am grateful for the benefits this brings to my patients. For those fortunate enough to be able to contribute, giving provides a sense of meaning, purpose, and relevance. It allows them to contribute to others, and the world, in an impactful way. It offers a language in which to express their appreciation. It enables them to learn about something they have a strong personal interest in, and to help advance knowledge in that area. And it gives them a different way to connect with me—not only as my patient, but on a different plane where we work together to solve medical quandaries that affect not just them but a wide world of others, present and future, who suffer similarly.

More Than Memories

Lauren Draper

Checking email as I wake up on Monday morning, I see the picture of one of my bald, smiling patients as the headline of an email from the hospital I work at asking for donations. It appears to be a mass email highlighting our work asking for continued support of our donor-funded programs. I briefly think back to her visit last week when we had to discuss ongoing weight loss and her uncontrolled nausea. None of that angst and pain is evident in her smiling face in the email. On the hospital social media page, I see another of my patients prominently featured with our hospital therapy dog, no trace of the tears that were present during his last hospital admission. Walking into the hospital, I see the framed pictures of former patients describing what they want to do when they grow up. I think of the ones featured that never had that opportunity to chase those dreams and wonder about those that have grown and what they are doing now.

In the hospital that day, I head into one of the rooms on the oncology floor, each room bearing the name of a donor, and this room with the name of a former patient and his family. As I enter this room to discuss a new diagnosis with a family, I cannot help but think of that former patient and smile to myself, knowing how well he is doing now.

Later in the day, as I take parents into our conference room to discuss the worrisome results of new scans, I am struck by the artwork and name of a patient that died years before my arrival at the hospital. Surrounded by his memory, but forcing myself to be present so this child in front of me will not succumb to her disease.

At the end of the day, while following up on emails, I see one from the hospital foundation asking if I can help take a potential donor on a tour of our unit. I wonder how a tour can possibly show them the breadth of what we do every day and the specialness of each of our patients.

After completion of treatment, families tend to fall into two groups, those that have no desire to remember, relive, or visit the horrifying memories—or those that lean into the hospital community. Sometimes those that lean in want to find ways to help other families walking the same journey, either through physical support or monetary donations. We see that same split in families, even for those whose child has died from their disease. As their medical team, we grapple with the different reactions and choices families make even after their medical care is finished.

In pediatric oncology, we spend years caring for these vulnerable patients and their families, working to gain trust during what is often the most difficult time of their lives. The trust that is earned often comes at the price of boundaries. The entire medical team often becomes an extension of the family, knowing the stressors and successes unlike those on the outside know. When those families lose their child, we mourn with them. While our

hearts are sad, we also have to go to work the next day and treat another child and family. Through the grief, we also have to go home and be present for our own families and attend to the tasks of our daily lives. Each member of the medical team has developed their own way to cope with the pain and loss. Some maintain a firm boundary at the hospital, protecting their heart so they can continue to treat children with life-threatening illnesses. Others lean in and use the grief as fuel to care for others. Most of us participate in (or are in desperate need of) therapy. Those grateful patients that wish to give back to the hospital present a unique challenge.

The grateful parent of a child that has died is often the most challenging for the medical team. Each child that has died holds a special place in our heart, not only of their memory, but also of our failure. Our job was to cure their disease, but we were unable to do that. We also know that most parents desire, after their child has died, to ensure the memory of their child remains. These grateful families that choose to engage with the medical team or hospital after the death of their child present an ethical challenge for the physician and institution. Families that wish to donate time or money after their child dies may be trying to fill a void or grief in their own way. Often, they are seeking connections to people and places where their child will be remembered. What role do the medical team and the institution have to protect the mental health of a family after the primary patient has died? Is there a subtle coercion that occurs when we take money from families in remembrance of their child?

I often struggle with these questions when faced with potential donors that are former patients. Though, each day I see the impact of those donations. The medical care of a child with a life-threatening disease is so much more than just the insurance-covered medicine and scans. It is the teacher who keeps them caught up with peers. It is the therapy team that provides support through play, art, and music. It is the psychology team that ensures their mental health is prioritized despite the other medical challenges. It is the toy closet that provides a place of reprieve after painful procedures. It is the kid-friendly decorations in the rooms and hallway. These pieces of their care are only available because of the generosity of donors. A former patient is in the best position to know the benefits of each of these programs and desire to provide those for other children facing the same struggles. Yet, the motivations behind grateful patient donations can be difficult to interpret. The stress families face through the course and aftermath of an illness of a child often leads to maladaptive coping techniques. Is the donation another form of maladaptation, albeit generous? Does the gift come with expectations?

These motivations become more entangled when the gift is from a family of a patient who has died. Most times, I believe, families give back to provide hope and comfort to other families on the same journey. It also provides an outlet to stay connected to the medical team and the institution that cared for their child. The gift also provides an ongoing, active memorialization of their child. Though, I always worry about these gifts.

Most importantly, how does the institution ensure the gift is used with purpose and honor? This can be accomplished with a well-run foundation meeting with families and donors and asking how they envision their gift being used. Expectations must also be set with families, so they know their gift will provide. The medical team is always happy to hear from former patients and families, but the institution should be mindful of the potential sadness these gifts can trigger in the team. Remembering patients that have died often has a mix of fond memories and the sadness tied to their loss.

As the physician, I have also had families of former patients ask me what to do with their donation. After they have been through treatment, many families struggle with how to proceed, even when their child is healthy and recovered. Many times, they start a foundation or received donations from friends and family. In the past, they have come to the hospital and me asking what we need. I am often at a loss for how to direct them. I can think of many needs the division or hospital has and can also think about the funding needs of research with the goal of new treatments. No gift will bring them true peace after losing their child, but I often try to go back to their child's favorite things and guide them in that direction for giving. I am thankful for

our hospital's foundation. While we do not have specific guidelines for gifts from grateful patients, the foundation is skilled in helping families give in a meaningful way. The foundation works closely with the medical team to meet with potential donors. This is a way for donors to see where and how their money will be used. I do think all members of the hospital that meet with former patients must be aware of the possibility for unintentional coercion. These families have been through significant stress and often feel very indebted to the hospital team for the care they provide.

There is not a perfect algorithm for families and hospitals on how to interact after the death of a child. The treatment relationship ends, but the medical team knows the family continues to suffer. The hospital continues to move forward and provide quality, compassionate care to all families. A donation from a grateful family can provide that family with some sense of peace and can provide comfort to other families going through the same illness. These gifts can serve as a further memorialization of their child. Though, we must all be aware of the undercurrents of these gifts. There can be many unintended motivations and consequences. Each day I walk into a children's hospital, and I am reminded of the presence of so many children who have walked these halls. I also see the patients in front of me benefitting from the gifts of generous donors, some of which are former patients, and I am grateful for those gifts and memories.

Targeting Patients for Donations: Opening a Door, or Pushing Them through It?

Michelle A. Burack

I was in the clinic hallway with my patient en route from the waiting room to the exam room for a routine follow-up appointment. I said, "Thank you again, *so* much, for your donation to the department in my honor."

"Sure, no problem," my patient replied. "Although I have to say, when I first opened the letter, it was kinda creepy. But I'm so grateful for your excellent care, that I felt like I had to send something."

I stopped in my tracks. "Wait—the hospital sent you something *asking* for a donation?"

I had been practicing at an academic medical center as a neurologist specializing in movement disorders for six years. I was at the awkward Assistant Professor level, feeling confident in the excellence of my clinical skill but still very junior in the power hierarchy.

I chose movement disorders as a subspecialty in part because of the long-term relationships we develop with our patients. Conditions like Parkinson's disease and dystonia are managed, not cured. During training, I looked forward to having the sacred responsibility of following "my" patients over the long course of their disease trajectory. We typically see people every three months for many years. It is a specialty that allows us, in the words of Hippocrates, "to know what sort of person has a disease," not simply "to know what sort of disease a person has."

Skillful use of available treatments requires attention to nuance: not only the subtle details of how the brain is controlling movement during everyday activities like writing, reaching, and walking, but also aspects of behavior arising from circuits in the brain governing mood, decision-making, and interpersonal relationships. Trust is essential for cultivating the close doctor-patient relationships that I rely on to identify how these diseases and treatments impact domains of brain function that are intimately linked to personhood.

After the appointment, I sent an email to the advancement office. "Can you please clarify—are our patients being targeted for donations?" I was informed that legislation passed the previous year made it possible for the advancement office to view the provider's name and department associated with a patient's most recent visit, and thereby use that information to send more targeted requests for donations. I was reassured that the reply slips included information on how to opt out of future fundraising requests.

I was distressed that the sacred space of trust that I so carefully cultivated with each patient was being breached by the institution without my knowledge or assent. Nearly a month passed before my outrage had subsided enough for me to write to departmental leadership to share my patient's feedback about the targeted solicitation feeling "creepy." I did my best to make the tone of my email constructive: "I thought you might want to know in case it weighs into future discussions regarding this fundraising tactic." In their replies, the departmental leaders highlighted the "delicate balance" between potential discomfort and making people aware of opportunities to support our mission. They acknowledged my patient's discomfort but also highlighted a recent $10,000 donation that they attributed to these solicitation letters. I was again reassured that patients were offered the opportunity to "opt out." The failure to notify faculty of these endeavors was acknowledged; one leader expressed that it would be "TMI" to inform us of every fundraising initiative, whereas another leader proposed sharing copies of future letters with us prior to mailing.

I reiterated my personal discomfort with the tactic, acknowledging that the level of discomfort in my case likely stemmed from "the very personal nature of the discussions that transpire over the longitudinal course of caring for people with diseases that threaten their very sense of self." I shared my opinion that offering patients the opportunity to opt out once they have received a solicitation is too late because "you can't un-creep people out." It would be better to allow providers the discretion to opt their patients out based on their knowledge of their patients' circumstances. I acknowledged that institutional leaders must factor the fiscal sustainability of the institution into such decisions—a perspective wider than my individual relationships with patients—and thanked them for allowing me to contribute my perspective.

Other than a brief mention at a subsequent face-to-face annual performance review, there was no further discussion. Three years later, I received another notification that one of my patients had donated, making me aware that the solicitations had continued. As the years passed and my reputation as a local expert in my field became more widely recognized, I was asked to meet with two people from the advancement office to discuss direct face-to-face solicitation of donations from specific wealthy patients in my practice. I refused, saying I would happily facilitate a *patient*-initiated request but would never initiate the ask.

Although it was neither the first nor last moment of disillusionment in my 11 years at that institution, discovering that my clinical relationships were being leveraged for fundraising was the beginning of a fundamental shift in my attitude toward work. Prior to this moment, I was willing to sacrifice time with my young children to put in long hours; afterward, I noticed myself being more conservative with my time and energy investment toward institutional priorities. (I have always been willing to invest extra time and energy for patient-centered needs.) The lack of transparency around how the donated funds were being allocated contributed to my sense of betrayal. Year after year, I begged for support that would have made me more effective clinically and academically, but was told we couldn't afford it. I can only wonder how differently my career might have evolved if I had been more willing to be complicit in soliciting donations from patients.

I resigned from my position at that institution in 2019. In February 2021, news broke that the institution had inappropriately expedited access to the COVID vaccine for wealthy donors. This immediately re-activated the unhealed moral injury from 7 years prior. I have remained in touch with the patient who made the donation in my honor, and I reached out to ask her what she thought about this news story. Specifically, I wanted to know if *she* had felt that donating would in any way change the quality of the care she received.

> I remember thinking it was strange that they were asking me to donate money since I was a patient. I felt compelled because I thought it was something I was expected to do. Part of it is that I really appreciated what you have done for me, and so I also felt that it was important to recognize you. But it did feel really strange to get something that basically felt to me like it was saying, 'You come here, you're a patient; are

> you grateful? If you're grateful, then you should donate.' I did feel that the doctor-patient relationship—which was a *continuing* relationship because I have to come in and see you—made me feel that strong pull to donate the money. When they ask you for a donation, if you *don't* give and you have an ongoing relationship with the institution, it does feel a little distorted. If it just came from the institution [and not your specific department], I don't know that I would have donated. And [regarding the possibility of receiving extra TLC if you are flagged as a donor], it actually happened. So there you go.

Unlike relationships with other entities that receive philanthropic donations, a patient's relationship with a healthcare institution is *non-discretionary*. Healthcare is essential, not optional. This results in an inherent power differential that can put undue pressure on individuals who are in a vulnerable position. Moreover, because doctor-patient relationships presume that the best care is being provided regardless of financial status, any hint of preferential treatment erodes trust not just between individuals but also in institutions that provide these services. The layers of betrayed trust—between the institution and myself, and by proxy between my patient and me—fundamentally undermined the foundations of integrity that I aspired to uphold professionally, and ultimately was a significant factor in my decision to resign from my academic appointment.

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An Attitude of Gratitude: The Physicians' Role in Philanthropy

James Malone

I am the Chief Medical Officer at French Hospital Medical Center in San Luis Obispo, California and practice medicine with a specialty in hematology. About five years ago, we started actively engaging in grateful patient giving at French Hospital. A consultant came to meet with us to set up a formal program. He explained that the foundation needed to enlist the help of the physicians in this community to be alert to situations where patients and their families may be expressing gratitude and what we could do, as physicians, to validate that gratitude.

People would say to us, "Thank you so much for the care, it means a lot." and we were used to saying "Oh it's nothing. It's fine." But research shows that's a big turn off to people. Expressing thanks is their attempt to give you something and putting your hand up and saying "we're just doing our jobs," is like turning away a housewarming gift.

We learned that you have to understand how to receive praise, thanks and gratitude graciously and how to say, "You're welcome."

We also learned that it's OK to make a referral to the experts in our foundation when someone wants to volunteer or give other resources as a way of showing that gratitude. I'm not the expert in that, nor should I try to be. Just like if I have a patient with a heart problem, I refer them to a cardiologist.

The biggest lesson I learned from working with our foundation is how important this is for people's healing process—whether they are having a good outcome or not. We want to provide heart care, cancer care, and also the care of their spirit and soul.

Sometimes our physicians will think getting involved with philanthropy is somehow unethical or wrong or that they are ill-equipped to do it. But we are in a unique position to hear people trying to express their gratitude.

Once I started changing my approach, I realized people did talk about this all of the time, but I wasn't truly listening for it. I needed to make that connection to what they were saying they wanted and how it was part of their healing. I don't ever talk to people about money. I listen and I say, "If you want to help us in the mission, come aboard." Then I introduce them to the foundation.

One great example is a patient, George who I was taking care of for the better part of 10 years. He had blood cancer and had many rough patches. His treatment included chemotherapy and bone marrow transplants. He was always talking about

how grateful he was. I decided to invite him to our big annual fundraising event—Share the Hope. He was at the point in his journey where he needed some inspiration.

Throughout the night, you could see how moved he was by all of the stories from patients and families and all the support that's provided. That night, during the call to action, George raised his paddle and made a significant gift. We had never talked about a donation. We didn't have to.

In cancer care, everything we do is at some "cost" to the patient. It's not lost on me that what we put people through can be punishing. That night, with George, I thought, "I just gave him some good medicine." Being involved in him making that donation and saying thank you helped me feel like we completed a part of healing that he needed.

George's story is an example that stands out, but there are many ways that being a part of our foundation's work—and specifically with grateful patient fundraising—has boosted satisfaction in my work and positively affected my relationships.

This work with fundraising can bring you closer to your patients, because it gives you one more thing you share with them—your love and passion for supporting the hospital.

Working with our foundation at French Hospital brings me great pride and satisfaction. As I walk around our facility, I see the names of patients on signs near waiting rooms and treatment areas and I know that I played some role in helping us improve our facility. This clear evidence of the support of our mission by our community encourages me even more to find meaningful ways to engage grateful patients.

I can see how we do a good job of taking any money made or raised and putting it back into the hospital. Millions of dollars have been put back into our infrastructure over the years. That's what is rewarding to me. Through the foundation and their storytelling providing opportunities to connect with grateful patients, you get to see how people in the community fully support our healing mission.

Since starting at French in 2005, I can see how these funds have helped improve both the aesthetics of our nonprofit community hospital and support the building of unique care capabilities. Our community has access to a level of service and care here that they couldn't before because we put capital resources into our facility and into building its programs. If we were not able to accomplish these important projects, patients would likely have to travel many hours away from home to access the care they need. which would add hardship to an already stressful time in their lives.

All of this helps build a culture of philanthropy. The patients give back. The caregivers get to be involved. New facilities, programs, and technology are created or improved. We all get to see what is made possible through donations.

I've seen our physicians and staff be inspired by this and also want to participate in philanthropy by donating their own resources. The French Hospital Medical staff committed $125K to our current campaign. I don't think they would have been willing to do that if they didn't see how their community was behind it, too, and making that connection comes from the grateful patient work we're doing.

Our ability to recruit and retain excellent physicians is also dependent on the hospital being able to provide modern facilities and state-of-the-art tools. So, philanthropy makes my job easier in recruiting new physicians because we have those tools and the reason we have those is because the community helped provide those for us through their generosity. I do tours for physicians who are new to our hospital or who are considering us as their place to practice and I show them the names on the walls, and I explain to them what was made possible by this person or that family and they get to really see that the community is behind it. I have seen numerous times how impactful this has been on physicians ultimately deciding to relocate to our area to practice.

As a physician in training, you don't learn about how a hospital works financially. You don't learn that to build a treatment center or acquire a new tool at a not-for-profit hospital that there is no built-in source of revenue for that, given the very narrow operating margins that acute care hospitals experience. Those funds come from philanthropy. No hospital based-specialist wants to work in a place where they couldn't get a new tool, and so part of my role, as I see it, has been to educate

around this with the help of my colleagues on the philanthropy team.

I understand there has been some criticism of some grateful patient work related to expected favors or pressures to accommodate donors. I can attest that I have never experienced that in my time working with our foundation. I know there are times when donor requests come to our foundations and those professionals are trained and equipped to respond appropriately. I think sometimes that's related to navigating what can be a complex healthcare system and the frustrations that arise from that.

In my experience, most people—whether they are donating to the hospital or not—want to be treated with care, kindness and respect. Being willing and able to respond to their expressions of gratitude is another way to show that we are committed to going above and beyond their expectations in their overall care.

It's been my honor and privilege to work with the fundraising professionals at French Hospital, led by my friend and colleague Debby Nicklas, to build our grateful patient program. I've learned the importance of instilling an 'attitude of gratitude' in all that we do. This process has been a priceless gift that has forever changed my perspective on what it means to be a physician.

At the Heart of the Matter: Transforming Gratitude into Giving

Jon A. Kobashigawa

When you're a heart transplant cardiologist, there's a special kind of symmetry that happens with your patients. They come to you for a new heart, and you end up giving them a piece of yours.

I love my job. I am the DSL/Thomas D. Gordon Chair in Heart Transplant Medicine, associate director of Clinical Affairs at the Smidt Heart Institute, director of Advanced Heart Disease, and director of the Heart Transplant Program at the Smidt Heart Institute at Cedars-Sinai. I take care of patients who are on the verge of death. With a successful transplant, they can walk out the front door appreciating everything around them anew. Seeing that transformation never gets old—it's a miracle every time.

In transplantation, a patient's journey starts with a gift—with the selfless decision made by families during a time of profound grief to donate the organs of their loved ones. Patients know this. It is difficult to articulate their sense of gratitude, but it is profound. This gratitude often translates into a desire to give back somehow and opens the door to philanthropy.

Approximately 74% of Cedars-Sinai donors are grateful patients—that says something about how our patients value the work that we do across the Cedars-Sinai health system. My program performs more adult heart transplants than any other program in the country (according to the United Network for Organ Sharing). Meanwhile, my institution, the Smidt Heart Institute at Cedars-Sinai, ranks number one in L.A., number 1 in California, and number 3 in the nation for cardiology and heart surgery, according to U.S. News & World Report. That success represents both the investment of time and energy by our expert faculty and highly experienced staff and the investment our patients have made over the years to support our research and educational outreach efforts.

Grateful patient philanthropy allows me to advance research by pursuing the most groundbreaking science, clinical trials, and emerging treatments that can be translated from the bench to the bedside. It allows me to educate and train the next generation of scientific and medical leaders by supporting highly competitive fellowships, residency, and training programs. It also allows us to build and expand facilities that better serve our patients and enhance their experience—and support important community programs that help underserved populations.

Asking patients directly for a gift can be delicate, but I know how much their generosity accomplishes. Ensuring that these initiatives are supported is an important part of the work because this is what allows us to deliver the best patient care and best patient experience possible.

To me, the key to grateful patient philanthropy is building a rapport with patients as people—especially by listening. I'm in a busy field; time isn't always a luxury. Giving attention to the "personal" and not just engaging around medical discussions is what creates connection and ultimately deepens trust. Often, patients will tell you exactly what they need from you, and it's not always medical expertise they are seeking. Staying attuned and responsive to them, to their needs as people, goes a long way. By strengthening your relationship with the patient, you can inspire them to better comply with medication regimens and follow-up visits. It also creates space for mutual exchanges, with patients becoming comfortable asking about my interests and hobbies.

This relationship allows me to talk about my research and provides a natural way to introduce the need for financial support. I am genuinely excited about the research we are pursuing, and I think my passion comes through when talking with patients. In my experience, patients like to hear about how research can help future generations and other people like them.

I generally don't do a hard ask, but rather I try to paint a picture of what's possible with continued support. If a patient expresses an interest, I will suggest connecting them with our Development team, who are there to work with the patient to find the most meaningful opportunity for them to give back.

I recall a case of a young woman who had a lot of antibodies (small molecules that attack a donor heart). This meant having to find a donor that the antibodies wouldn't reject. The patient initially went to her local hospital, and they told her it would be nearly impossible to find a match and she should prepare for the worst.

Because of research we've done at Cedars-Sinai in antibody-mediated rejection, we took on her case. We performed a transplant, and she did have some rejection, but we were able to mitigate it. Now she's three years post-transplant and doing well. Her father understood that our success was due to advances in research and that research came with a cost. The family donated to further our pursuit of tolerance, the holy grail of transplantation, where the body doesn't need any anti-rejection medication. For this patient and her family, it was a very meaningful way to give back. It's a great example of how personal experience, gratitude, and philanthropy can align for the benefit of all.

Patients who give really care about science and supporting me and my team's endeavors at the Smidt Heart Institute. Grateful patient philanthropy at its core is about helping others help themselves. We need these programs to continue building a culture of philanthropy. They educate our staff on how to engage with grateful patients to support our philanthropic efforts and move the needle on groundbreaking research and patient care.

Equally important, grateful patient philanthropy requires you to be a good steward of the gift, making use of the money to its fullest, as well as maintaining a relationship with the donor. For instance, I hold an endowed chair in heart transplant medicine, which is an incredible honor. These funds have been a tremendous resource, supporting many initiatives, including multiple expert consensus conferences to help answer clinically relevant questions in the transplant field, resulting in the development or refinement of national guidelines. We provide a detailed report of these activities to the donor annually, keeping them informed and involved. In addition, we started a tradition of giving the donor a small silver heart decal for every patient transplanted that year—a visual reminder of all the very real people their gift has helped. While the donor is glad to hear that their gift is pushing the science forward, it's the more than 1,000 silver hearts in their collection that resonates most.

I don't consider myself a fundraiser, but these interactions are an important part of the work. Generosity from grateful patients helps push the boundaries of medicine and deepens my sense of professional responsibility. My commitment to research *is* my commitment to patients—those who walk out the front door today, and those who appear on our doorstep tomorrow in need of our help. The care they need and deserve depends on our ability to improve our understanding of disease processes, explore emerging therapies and hand the next generation of practitioners a strong foundation of knowledge to continue this important work.

At the end of the day, expressing gratitude through giving is a part of a patient's journey too—a journey I am grateful to take with them.

Neuroethical Considerations in an OCD patient undergoing Deep Brain Stimulation

Brent R. Carr

Two electrodes are buried deep within the patient's brain. I am using them to create miniature electrical fields that will manipulate the information flow of the brain's neurons. The target (the anterior limb of the internal capsule/nucleus accumbens) shares surprising proximity to that coveted area during those crude and controversial psychosurgeries of the 1940s. It is winter outside. Now with my relaxed patient in our warm office, I use the electrodes to systematically weave an expanding electrical spider web, meticulously noting the effects of every manipulation of electrical dosing on its shape utilizing these electrical threads. This is a region of the brain where minuscule changes of a tenth of a microvolt here or there could stimulate or inhibit neuronal pathways that might potentially induce states of immediate distress, intense euphoria, or precipitate abnormal movement. Precision and patience are essential, such that we will spend the next 2–3 hours together. I have an inkling of the rudimentary shape that this electrical spider web may need to have, as I was in the neurosurgical operating room when we interrogated the implants with varying doses of electricity while soliciting feedback from the awake patient. Now, some weeks later, I need to refine the settings to provoke the desired effects.

There is no science fiction here. And for those of us trained in the modality of Deep Brain Stimulation (DBS), it seems mostly . . . routine—the fiction dissipating in proportion to the rise in scientific understanding. However, seldom do these often seen, profound responses feel routine. DBS (which I am utilizing in this patient) can deliver astounding improvements for treatment refractory patients with movement disorders and obsessive-compulsive disorder. Years of torture from days-long intrusive obsessions. Repetitive compulsions, never thwarted by multiple medications. Years of psychotherapy, never buffering against the torment of invasive, unwanted thoughts. These have led the patient here. Finally, an initial response! Albeit small, the first in ten years.

It is nearing springtime now, and the initial gains for the patient have been sustained. It is almost as if the season is heralding in the potential for a new phase of life. Would these gains become durable? The response has churned up flitting sands of guarded optimism and gratitude that briefly expose themselves only to be engulfed again in waves of skepticism and fear of relapse. This sea, formed from a lifetime of anguished distraction, is not going to recede so easily. Yet, with each subsequent visit, I see the waves calming. We are making progress. Just as happens with other physicians and their grateful patients, I am praised for my skills and my intellect, and I graciously accept the compliments. But I also defer ownership of the response, pointing out the enormity of my patient's own efforts. Our doctor-patient relationship is within the luxury of academic medicine, where my educational institution allows for innovations and novel treatment. My patient clarifies the compliment further—an appreciation of the time commitment I always yield for the optimization of the DBS settings.

The patient taunts me that I should make much more money in the private sector. I smile and feign a slight surprise, stating, "Perhaps, but I will just settle with my very meager wages here and carry on to my exciting neuromodulation conferences just the same." We laugh and schedule a follow-up visit.

Summer is almost over now, and our response is holding, but a few more long sessions are looming over autumn. At the end of the visit, this grateful patient approaches me with an unsolicited donation, a check made out to me personally (<$5,000). It is a gift to me for the management of care. The sincerity of the donation was explicitly stated as a desire motivated to enhance the field of

neuromodulation and for me to excel while I participate in it. The check is written in my name to foster my personal education and conference travel for the same. I am equally flattered and reticent to accept the donation. My thoughts flurry as to whether this desire to reward me is for my fund of knowledge or our current successful outcome?

Should the gains begin to wane, would there be regret? Is it merely for an assurance that the same rigor in upcoming sessions will continue? Would it be disrespectful to refuse a sincere donation? Many patients have reported feeling empowered through the armament of their provider with the tools necessary to help defeat their illness. The importance of this should not be undervalued. I decline the check and offer my sincere appreciation, referring the patient to the Development Office for donation at our institution.

I contemplate whether this referral of the donation to that office is an ethical punt. Should I spend more time exploring the motives of the donation? How much time would be warranted? Is it some fickleness of personality wherein arises my discomfort of solicitation of monies from patients? Perhaps I am merely impoverished in training related to donations. I have received donations at other institutions and had similar hesitation over what the appropriate navigation should entail. How critical is it to individually foster donations? The field of DBS benefits vastly through charitable donations by individuals and families, many of whom have suffered from the very illnesses it targets. Generous philanthropy has helped to establish and move this field forward. Here, at my institution, I am indulged by a carefully planned development office that allows for philanthropy outside of the immediate clinical setting and disentangles donation from the immediate alliance with my patient. Its personnel are sensitive to patient wishes while maintaining a proficient optimization of donor options. At least that is my assumption; though I admit, I have not vigorously examined this. It seems quite tidy. Perhaps too tidy is merely the laid-back ethical path—a peculiar notion. Certainly, that development office would be better equipped to handle the donations than I with my meager history of a scattering of lectures and a handful of CME training on the topics of patient gifts and donations from drug reps. For me, these lectures fail to capture the complexities and uniqueness involved in each case such that it renders the training superficial. But, how much training, if any, should there be, or could ever be enough? How does one appropriately nurture an act of philanthropy that is germinated within the doctor-patient relationship if not by the physician? Might not a physician through nurturing donation contaminate the rapport such that the doctor-patient alliance suffers and becomes malnourished at the expense of the donation? The patient and I continue our clinical journey.

It is winter again, and the development office is now contacting me requesting an interview. A second donation has been made in my name from this grateful patient. They are interested in further exploring the individual's desire for philanthropy and would like to be diligent about the appropriateness of potentially approaching the individual to optimize further any desire to donate. One might have thought the neuroethical issues surrounding the modality of DBS itself, such as transforming personalities/identities and human bionics, might be the more prominent issue regarding any philosophical discourse for this case. But the ethical considerations of the donation were proving particularly complex. Was there any obsessional or compulsive component to these donations? After all, this was the primary diagnosis. Yet, the patient is autonomous. Would it even matter whether this donation might be motivated through altruism versus enlightened self-interest?

I processed this donation with other neuromodulation faculty and again met with the patient to discuss this theoretical future contact by the Development Office. This was politely declined by our patient, with the preference being the status quo. I did not energetically market the development office, not wanting to appear coercive or steer the choice. Had I undermined the potential donor? Was our patient now responding with what was perceived as hesitation to use the Development Office? Had I projected some uncertainty onto the patient?

Psychoanalysts might say this appears to be over-processing of the donations and was obsessive, arising merely as a manifestation of the projection of the patient's symptoms of OCD. Are we both now to be in a hastening vortex of projection and counter-projection whose centripetal force would send spirals of coins flying out of pockets? Even if such an absurd vortex could exist, it would subside once the relationship is reframed—physician and patient. I choose to maintain focus solely on the treatment, maintaining my doctor-patient relationship. We discuss blinding me as to whether there will be further donations by the patient, who now is without trepidation of being contacted or solicited any further—a quite tidy solution.

The seasons are nearing change again. There is a plea for an urgent visit. No availabilities exist for several weeks, yet though urgent, this is no imminent emergency. Our conscientious clinic manager, the same who is aware of the initial personalized check, is scouring the schedule for openings and asks if a clinic afternoon should be cleared. Before any such discussion can occur, a patient cancelation leads to an opening within 48 hours of that plea. And now we are here, at that cancelation. Our brief visit was successful, and all is well. The patient expresses gratitude for being seen on such short notice. Upon departure, the patient places something on my desk and reports remembering that I mentioned that I preferred not to have donation checks written out in my name. The patient's brisk retreat prevents any response. I now sit staring at a thick, white, unmarked envelope fattened with large denomination bills that have slightly spilled onto my desk.

To Give is to Receive

Kenneth R. Adler

I have practiced Hematology Oncology at Morristown Medical Center for more than 40 years. A community hospital for many years, Morristown Medical Center is now a Level 1 Trauma Center and—if you believe the editors at US News & World Report—the top hospital in New Jersey.

I have cared for the uninsured, the solid middle class, and the very well-to-do. Many people who sought care from my practice have been nationally known in the public eye. Whatever their backgrounds, every single patient received concierge-style care well before there was a name for it. We offered our time, attention, and compassion in the face of diagnoses that often inspired anxiety and grief.

Our patients appreciated our care and appreciated our team. Over the years, we received hundreds of cards, flowers, and home-baked sweets. One gardener showed up every summer with a delivery of giant eggplants, tomatoes, and peppers from her prolific garden. An astronaut sent me a photo of New Jersey from space. Artists arrived at appointments bearing watercolor paintings, and once, a small carving of a seagull. One time I even received Holy Water from Lourdes and was implored to share it with others. With each gift, each person in my care showed me a bit of him or herself that I wouldn't have otherwise seen.

This was true too of other patients and family members, whose offering was less tangible: a hand on the shoulder, a look in the eye, a weekend phone call out of the blue. "What more can we do for your practice? For your institution? For you?"

I never initiated the conversations, but I knew how to respond. After all, when calls arrived, the voices on the other end were ones I knew well. They'd come at the end of a long journey we'd walked together, a product of relationships developed over years, and sometimes decades, with families for whom I'd cared across two and occasionally three generations.

We'd spent years building an authentic, caring connection based on trust that had helped the families navigate some of their most difficult moments. They were calling now to ask that I help them extend one last gesture of care: A way to honor the memory of their loved one. That these gestures would eventually translate to dollars—millions of dollars—for my institution never gave me pause.

My patients felt good about supporting the hospital where they and their family members had received care. I felt good about giving them a way to express their gratitude and honor their loved ones. What's more, the health and wellbeing of our entire close-knit community—a community where I'd been fortunate to practice for many years—would benefit from that support.

So when patients or family members called and asked to "help," I knew what to do. I'd reach out to our hospital's foundation staff and let them take it from there. I never reviewed wealth-screening reports (though I was invited to do so) and never experienced any pressure to exploit the trusting relationships that both my patients and I held sacred. Whether the projects funded by our "grateful patients" were relatively modest, as with our patient-education and arts programs, or monumental—we added both a comprehensive cancer center and a children's hospital over the years—was inconsequential. It was the programs that mattered. I'm proud of the far-ranging impact my "grateful patients" have had. Their generosity has enabled—to name just a few: an early integrative medicine initiative, a national pioneering music therapy program, and a partnership with the American Cancer Society that brought an oncology nurse navigator to help support our patients. The benefits bestowed by the privileged few accrued to all, improving the range of services and the level of care available to the community at large.

As a lifelong volunteer in many local, state, and national hospice and patient-services organizations, I always considered the time and effort spent on fundraising work as one more way I could contribute to improving cancer care for all.

For me, it was always about the community.

Needless to say, COVID has changed everything. Some weeks I have more conversations with patients about vaccination than I do about chemotherapy. I find myself extending as much support to colleagues as I do my patients as we work to sustain each other through the mounting stress and burnout that arrives with each pandemic surge. As I approach the end of my clinical career, I have much to be grateful for. I derive great personal satisfaction from the contributions I have made, and I am grateful to my patients—to my "grateful patients"—for the part they've played in making them possible.

Grateful Patient Fundraising: Perspectives from a Development Professional and Physician

Cheryl J. Hadaway & Kevin E. Behrns

Introduction

The ethical engagement of physicians in a grateful patient's philanthropic journey has long been debated. With this narrative, we will lend guidance on physician collaboration with the development team. As a physician and development professional, we promote a path that leads to an ethical and successful patient engagement and provides a deeply meaningful experience for the patient. Whether the physician actively engages in the philanthropic process or assumes a diminished role, the physician plays the most trusted and vital role in creating the grateful patient experience. Importantly, this text demonstrates the mutual fulfillment experienced by the physician and grateful patient during philanthropic engagement. For the grateful patient, the journey may profoundly affect healing and emotional well-being.

How to Engage the Grateful Patient

In caring for patients, clinicians develop a unique relationship that is based on trust. Patients trust physicians will use their medical knowledge and judgment to provide high-quality care delivered with an empathetic bedside manner. The key to the development of trust is building a relationship in which the physician understands the patient's needs, and the patient understands the treatment options and associated risks. Clearly, building a relationship with a patient is based on good communication between the parties. A critical element in good communication is the physician's listening

skills. Only if the physician listens intently to the patient's needs will the relationship develop, and the patient have a satisfactory experience. As a pancreatobiliary surgeon performing high-risk operations for patients with pancreatic cancer, direct communication that clearly describes the benefits and risks of an operation is paramount to a trusting relationship. Up to 50% of all patients undergoing a major operation for pancreatic cancer will have a complication that you will need to discuss with the patient. This conversation is meaningful to the patient who received a forewarning in the preoperative discussion, and the patient will respect the surgeon that speaks directly to them and is open and honest. This direct conversation, however painful, builds trust. This interaction also shows the patient that you will be there for them when times are good or bad.

Engaging the grateful patient differs little from rendering outstanding clinical care in that interacting with a grateful patient requires a relationship built on trust. When a patient has an exemplary experience, they may express interest in supporting physician- or institution-led endeavors. The physician should listen intently to the patient's cues that may suggest a desire to support initiatives. These clues, though sometimes subtle, may open the door for philanthropic discussions. For example, the patient may say, "If there is anything I can do to help you, please let me know." One patient, who never had an operation, was grateful for the immediate clinic visit that was offered, and he wished to give back. He was interested in supporting our trainees, and he enjoyed interacting with them. As a result, he regularly funded education events, and we would invite him to interact with the team and develop a relationship. He was truly grateful to have a connection with the next generation of surgeons.

Patients may also ask questions about your position, your work-related passions, or about the team of providers that you are leading. Take note, and do not be bashful about discussing your interests and passions. Let the patients know your professional interests, but do not proceed further without the development professional. Let the patient ponder your discussion and approach them later if they do not express immediate interest. The discussion about giving may be initiated in the hospital or clinic, but it is best if it is continued in a social setting. For those patients that express interest, follow up is important. Most often, we try to meet patients in an environment comfortable for them. We prefer follow-up meetings in the patients home, but would meet them at other social venues or restaurants if desired. When the patient expresses sincere interest, further discussions should be led by the development professional. To reiterate, the crux of philanthropic engagement between a physician and patient is an emotional and caring bond based on trust.

Who Should Engage the Grateful Patient?

Physicians play a significant role in identifying and introducing the development professional as a member of their team. At the onset of involvement, the development professional should discuss with the physician their desired level of engagement—do they wish to be informed of philanthropic activity with their patient, do they wish to engage and to what degree, or do they wish to not be involved? Once the degree of engagement is confirmed, the development professional has the responsibility to communicate accordingly with the physician. If the physician wishes to be engaged, communication includes keeping the physician informed of relationship advancement, the commitment of a gift, physician acknowledgment of the donation, allocation of a gift, etc. Since most grateful patients anticipate their physician is informed of their philanthropic activity, it is important for the physician to share with the patient their preference for engagement in the philanthropic relationship. No matter the physician's engagement, grateful patients recognize outstanding collaboration between their physician and the development professional furthering their trusting relationship.

Preparation and Training for Grateful Patient Engagement

Physicians are among the most highly trained professionals, yet their training does not address the special attributes needed to interact effectively with potential donors. Like all professional duties,

embarking on philanthropic pursuits without training is not likely to be successful or enjoyable. Development professionals spend their careers learning how to cultivate patients as donors. As providers, we should learn from their years of training and experience.

The training and preparation necessary to engage patients may occur through many mechanisms. Many institutions provide onsite courses in which development professionals spend hours or days with physicians eager to learn about approaches and techniques to patient engagement. Not all institutions, however, provide such support. Most often, the instruction is for physicians who are engaged and wish to learn more about philanthropic efforts. It is not uncommon for physicians to have limited interest in philanthropy. If physicians lack interest, required training is futile. Philanthropic education should be directed at the physicians who are desirous of further knowledge.

An alternative mechanism is to work closely with a development professional to understand how they evaluate prospective donors and begin conversations about philanthropy. Regardless of whether training and preparation comes through a group experience or from an individual mentor, the training is not a one-time crash course on how to solicit funds from a patient. The clinician should anticipate studying the discipline through reading pertinent material, watching instructive videos, and by carefully observing development professionals exercise their craft. Finally, practicing behaviors that thoroughly prepare the physician for an encounter with a potential donor is important. The clinician should anticipate questions from the donor and know their ask of the donor. A carefully prepared and rehearsed script that does not contain medical jargon is a good start to show the donor the seriousness with which you take philanthropy. Preparation and practice are paramount to demonstrating your ability to engage the patient in a meaningful discussion and relationship.

Benefits for the Grateful Patient

From a grateful patient perspective, philanthropy provides an opportunity for the patient to express their gratitude to the physician, the physician's team, and the healthcare organization. In addition, patients may express interest in patient care, research, and/or education programs or campaigns. Grateful patients take pride in having a close relationship with their physician, and philanthropic engagement will even further augment their relationship.

Importantly, when grateful patients experience broader and deeper engagement with an organization, they are more likely to engage philanthropically and to a greater degree of significance. Their physician plays a key role in encouraging and expanding the sphere of engagement. Engagement experiences can include introduction to a development professional, offering behind-the-scenes tours of research labs of interest, introduction to key organizational leaders, etc. An open and trusting partnership between a development professional and a grateful patient will establish a philanthropic experience that can be developed strategically in a respectful and meaningful manner and result in long-term philanthropic engagement.

For many grateful patients, philanthropic engagement is therapeutic—they wish to give back in gratitude for their care, despite their healthcare outcomes. Grateful patients frequently contemplate the impact of their philanthropy for other patients—those for whom they will never know. A memorable philanthropic experience often enables the grateful patient to experience the highest degree with self-actualization; many grateful patients describe their philanthropic experience as a pinnacle in their lives. Patients with life-threatening illness like cardiac disease may be introspective and want to fund services or facilities that will enhance the care of future patients. One such patient made a substantial donation to create an operating room suite in a new hospital. The patient was thrilled to see the finished product that would deliver state-of-the-art care to future patients with heart disease.

Benefits for the Engaged Physician

The process of engaging a patient in philanthropic endeavors is educational and enjoyable. Securing a gift from a patient is even more gratifying

primarily because it leads to further development of the relationship. A patient's gift for research or educational programs should be accompanied by at least an annual interaction with the benefactor to demonstrate the progress of the project. Regular meetings with the donors promote the relationship and may lead to further gifts.

Aside from a gift from an individual patient, the process of gaining proficiency in philanthropic activities allows the physician to gain knowledge and confidence with the discipline. Once significant experience is obtained, the knowledge and skill set attained can be shared with other physicians. Creating an environment that realizes the benefits of philanthropy establishes an ever-evolving environment that creates a culture of philanthropy. Once established, this culture perpetuates philanthropy as an integral function of the medical center. Healthcare environments that create an atmosphere of giving often function at the highest level and have resources to invest in innovative programs in education and research that propel the organization as a top performer.

While the benefits to the physician may be great, a word of caution is necessary since not all engagements with grateful patients will flourish. First, it is important that the physician be completely transparent in the relationship and not make promises that are unrealistic, or grant favors that other patients will not receive. Second, the physician may spend many hours with a potential donor but never consummate the relationship with a gift. The physician should view this outcome as just part of the process and their education in philanthropy. Negative feelings toward the patient or program will not lead to better outcomes in the future. Like all experiences in medicine, philanthropic endeavors may have humbling results, but the physician should take the lessons learned and continue to engage potential grateful patients. One patient, a retired surgeon, was interested in funding an endowed chair that held his name. We met with him countless times and provided several proposals, but in the end, he did not wish to support the endowed chair. Though disappointing, we had several insightful meetings and developed a friendship, which itself is valuable.

Definition of the Roles of the Physician and Development Professional

Providing the grateful patient with a meaningful philanthropic experience is best accomplished when the physician and development professional have clear roles and responsibilities in managing and advancing the patient's philanthropic relationship.

Physicians play important roles in identifying prospective donors, cultivating the relationship, enhancing engagement with the organization, and fostering stewardship of the patient's philanthropy. Direct involvement in the solicitation requires careful consideration. Ideally, the physician is not actively involved in the solicitation in order to protect the sacrosanct patient-physician relationship. The development professional should serve as the solicitor working collaboratively with the physician to gain their knowledge and recommendations that may be crucial to a successful outcome.

Physicians who actively engage in the philanthropic process also play a vital role in the best practice fundraising education of their peers. Sharing with peers their fundraising success stories and collaborative relationship with the development professional will further build trust and confidence in the philanthropic process. Engaged physicians can convey to their peers with far more success than the development professional the importance and impact of philanthropy on patient care. Conversely, the physician serves to educate the development professional on the physician's perspective. Such mutual exchange serves to further refine the physician and development professional relationship and, importantly, offer the grateful patient an even more rewarding and joyful philanthropic experience.

Creating a meaningful and trusting relationship resulting in a philanthropic gift takes time, especially when gifts of significance are being sought. Physician demands often make such investments of time challenging. The development professional plays a key role in strategically engaging the physician at the right time for the right purpose. The development professional serves as the philanthropic relationship manager and, as such, is responsible for advancing the philanthropic relationship and engaging the physician according

to their wishes. Importantly, the development professional plays a key role in managing expectations with the grateful patient and removing the physician from difficult situations in order to preserve the patient-physician relationship. As an example, a grateful patient wished to donate a substantial gift and the involved surgeon wanted the gift to be directed toward his interests. The size of the gift, however, was large and not appropriate for the surgeon's narrower interest. In this case, the development professional managed the gift such that it was directed at an institutional project that was appropriate for the size of the gift and also provided benefit to the surgeon.

The development professional and their team hold the responsibility to develop a culture of philanthropy within the organization. Foundational to a culture of philanthropy is educating the physician and allied health staff on philanthropy—its purpose, importance, and impact on patient care, research, and education.

Advancing a culture of philanthropy requires each staff member's understanding of their role in creating a grateful patient environment. Within health care organizations, the philanthropic team is often recognized for their successful philanthropic outcomes. Such success is only possible when every member of the organization takes responsibility and is recognized for their contribution. When a culture of philanthropy is practiced in an organization, the philanthropic impact will be realized, and the satisfaction of the grateful patient, their physician, and the entire health care team will reside in perpetuity.

Conclusion

The grateful patient is too often forgotten as an indispensable resource in the medical center. Thoughtful cultivation and careful preparation of a program that engages the grateful patient will yield dividends far greater than dollars. The relationships developed will create positive feelings toward the physician, development officer, and institution. Furthermore, grateful patients often interact with other grateful patients or donors of means, and a network of philanthropists who praise the individuals with whom they interact, and the healthcare center, expands.

The foundation of a development program is the department of development, its leaders, and professionals. While physicians may be integral to the process of securing a gift, the development professionals have the time, talent, and expertise to establish the culture of giving and the program. Physicians should partner closely with development professionals if a grateful patient is viewed as a prospect, and, jointly, they can engage the patient and bring all their talents to the partnership.

A grateful patient program may result in rewards far greater than monetary gifts. The overwhelming positive culture created by the program will establish momentum for future giving and lead to investments that may catalyze the development of top-tier programs.

Commentary
Narrative Themes in Grateful Patient Fundraising

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Abstract. In this commentary article, I will identify and examine a variety of themes that arise in narratives written by 12 physician authors that detail their experiences with grateful patient fundraising. Grateful patient fundraising serves an important role in health care philanthropy. Donations by grateful patients offer practical benefits to society and altruistic giving can personally benefit donors and family members; however, solicitation of donations by physicians raises a number of legal and ethical issues including, concerns about equity and health information confidentiality. To prevent eroding or distorting the physician-patient relationship, physicians involved in grateful patient fundraising must adhere to ethical guidelines and recommendations.

Keywords. Grateful Patient Fundraising, Health Care Philanthropy, Societal Benefits, Altruism, Physician-patient Relationship, Health Information Confidentiality, Wealth Screening, Non-monetary Donations

Introduction

In this commentary, I will identify and examine a variety of narrative themes that relate to grateful patient fundraising. These themes include acknowledgment of the practical benefits to society of grateful patient fundraising; recognition of the personal benefits that flow to patients and families from altruism; widely variable forms and levels of fundraising training; physician understanding of the potential ethical concerns raised by grateful patient fundraising, including erosion or distortion of the physician-patient relationship, equity concerns, and health information confidentiality concerns; and varying opinions and practices regarding wealth screening and non-monetary donations. I will conclude by highlighting narrative recommendations for minimizing ethical concerns relating to grateful patient fundraising.

Benefits to Society

Several of the narratives expressly acknowledged the practical benefits to society of grateful patient fundraising. Identified benefits include, but are not limited to, support of research, education, clinical programs, community programs, and bricks-and-mortar facilities. Grateful patient philanthropy allows Jon A. Kobashigawa, for example, to pursue the most groundbreaking science, clinical trials, and emerging treatments that can be translated from the

bench to the bedside. Grateful patient philanthropy also allows Kobashigawa to educate and train the next generation of scientific and medical leaders by supporting highly competitive fellowships, residency and training programs. Philanthropy also helps Kobashigawa and his colleagues build and expand their facilities to better serve their patients.

Kenneth R. Adler also acknowledges the tremendous impact his grateful patients have had on clinical initiatives, therapy programs, and health care resources. Adler's patients have helped to build, for example, an early integrative medicine initiative, a national pioneering music therapy program, and a partnership with the American Cancer Society, the latter of which supported an oncology nurse navigator position. According to Adler, "The benefits bestowed by the privileged few accrued to all, improving the range of services and the level of care available to the community at large." Reshma Jagsi agrees with Adler: "Society as a whole stands to benefit when hospitals, especially academic medical centers, gain resources to pursue their clinical, educational, and research missions of service to the community." Ahmet Hoke states, "Individuals in the United States, collectively, give billions of dollars each year to the country's medical centers. The significance and impact of their giving cannot be underestimated; they make a huge difference for institutions, medical knowledge, and future patients."

Although senior physicians may see, over time, the multiple ways in which grateful patient fundraising can benefit society, younger physicians, including physicians in training, may not fully understand the role of philanthropy. James Malone explains, for example, "You don't learn [in training] that to build a treatment center or acquire a new tool at a not-for-profit hospital that there is no built-in source of revenue for that, given the very narrow operating margins that acute care hospitals experience." According to Malone, "Those funds come from philanthropy."

Benefits to Patients and Families

Several of the narratives recognize that altruism can benefit patients and families. As explained by Ahmet Hoke, "Mrs. Jones was one of the first patients to open my eyes to the fact that philanthropy can benefit not only my research, my institution, and me professionally, but also the donor." According to Hoke, "She wanted a way to say 'thank you,' and making a financial gift enabled her to do so. I directly witnessed the personal fulfillment she gained from this philanthropic act." Hoke further notes that, "For those fortunate enough to be able to contribute, giving provides a sense of meaning, purpose, and relevance. It allows them to contribute to others, and the world, in an impactful way. It offers a language in which to express their appreciation. It enables them to learn about something they have a strong personal interest in, and help advance knowledge in that area."

That altruism can benefit patients and families was recognized by several other authors. Brent R. Carr states, "Many patients have reported feeling empowered through the armament of their provider with the tools necessary to help defeat their illness. The importance of this should not be undervalued." After sharing her initial attempts to protect patients against the ethical challenges associated with grateful patient giving, Reshma Jagsi explains, "But maybe in my attempts to protect against the ethical challenges of such situations, I have been inadvertently robbing my patients of an opportunity to feel empowered by the exercise of altruism."

Widely Variable Forms and Levels of Training

The narratives reveal widely variable forms and levels of fundraising training. Some authors report receiving no training, some report meager training, others report experimental training, and still others report significant training. Brendan D. Curti falls into the first category as he received no formal training relating to grateful patient fundraising. Brent R. Carr falls into the second category in that he has a "meager history of a scattering of lectures and a handful of CME training on the topics of patient gifts." Carr also notes that these scant lectures and trainings "fail to capture the complexities and uniqueness involved in each case," and he ponders,

"But, how much training, if any, should there be, or could ever be enough?"

Ahmet Hoke falls into the third category, having received training through an unusual (scientific) door. That is, Hoke participated in a research study that investigated three different means of engaging physicians in grateful patient fundraising, including a web-based module, a group lecture, and one-on-one coaching. Study participants like Hoke received training in one of the three methods for six months. As explained by Hoke, "The coaching I received—now a 'curriculum' that my institution provides to all—informed me about the stages of a gift cycle, namely, identification, engagement and cultivation, solicitation, and stewardship."

Other authors report receiving (or providing) significant training. For example, James Malone and his colleagues used to provide modest responses to their grateful patients, such as "'[W]e're just doing our jobs'" or "'Oh, it's nothing. It's fine.'" However, they learned through training that their modest responses could be perceived by patients and families as the equivalent of turning away a housewarming gift. Malone and his colleagues now have been trained to receive expressions of gratitude, validate those expressions of gratitude, and refer patients who express a desire to volunteer or donate to their institutionally-related foundation. Leslie Matthews describes the provision of similar training: "After warmly accepting an expression, the training continues to coach our providers to continue the conversation by saying something like, 'we have a number of projects ongoing that are very important to me. If you would like to learn more about them and how you might help, then I'm happy to connect you with my colleague in Philanthropy.'"

Ethical Concerns Raised by Grateful Patient Fundraising

The narratives reveal a wide range of perspectives regarding the potential for grateful patient fundraising to raise ethical concerns. The narratives also reveal a wide range of practical experiences with such concerns. For example, one author reports experiencing no ethical concerns associated with grateful patient fundraising. As explained by Brendan D. Curti, "Never during my tenure . . . have I experienced medical ethical concerns about a grateful patient donor relationship. Foundation staff members have never asked me to invite a patient to an event or make any other fundraising 'move' as part of a clinical visit, and none of my patients have suggested I give them access to a different treatment in exchange for a financial contribution." Curti concludes that, "[E]ngaging patients in supporting our research has been remarkably uncomplicated and deeply rewarding, both professionally and personally."

Other authors recognize the literature that examines the potential ethical issues that may be associated with grateful patient fundraising. Reshma Jagsi, for example, reports that: "[E]thicists have articulated reservations about physician participation in encouraging donations from grateful patients out of several concerns. They are apprehensive of conflicts of interest, the inherent asymmetry of power in the physician-patient relationship that can lead to undue influence, concerns relating to privacy and confidentiality, and equity considerations relating to true—or perceived—differences in the services delivered to donors versus others."

Some of the authors report experiencing more discomfort (and/or more ethical concerns) before receiving training in fundraising. For example, Leslie Matthews acknowledges the initial discomfort of some providers: "Most often, this is incredibly uncomfortable for providers. As an orthopedic surgeon and Chief of Orthopedics for MedStar Health, I was of the same thought. For my colleagues and me, the idea of talking to a patient about a philanthropic investment felt like a breach of the doctor-patient relationship, unethical, and a HIPAA violation. As a physician, I did not want to be in a situation where I needed to ask a patient for money." Ahmet Hoke also acknowledges his initial (pre-training) discomfort: "Like many physicians, I initially had concerns about the ethics of asking patients for contributions to a doctor or institution that treats them. I worried that this might violate my commitment as physician to my patient, or that

the introduction of a possible financial interaction might jeopardize our clinical relationship. Most importantly, I wanted assurance that raising the concept of giving would not negatively impact the patient in any way." After receiving training, Hoke explains that "there is indeed a professional way—a way that is sound, boundary-preserving, and ethical—to practice [grateful patient fundraising]. When thus performed, [grateful patient fundraising] does not compromise the physician-patient relationship and can actually strengthen it."

Erosion or Distortion of the Physician-Patient Relationship

Some authors focus specifically on concerns associated with erosion or distortion of the physician-patient relationship. Joel S. Perlmutter, for example, explains that he is reluctant to initiate discussions with patients or families because he does not want those discussions to intrude on the patient-physician relationship: "In particular, I do not want to have any sense that I am coercing someone who depends upon me for care, nor do I want the patient to feel an obligation."

Michelle A. Burack believes that concerns associated with erosion of the physician-patient relationship are exacerbated by the non-discretionary nature of health care: "Unlike relationships with other entities that receive philanthropic donations, a patient's relationship with a healthcare institution is non-discretionary. Healthcare is essential, not optional. This results in an inherent power differential that can put undue pressure on individuals who are in a vulnerable position." Burack also explains that one of her grateful patients perceived a distortion in the physician-patient relationship when the hospital sent a department-specific targeted communication to the patient asking for money. According to Burack's patient, "I did feel that the doctor-patient relationship—which was a continuing relationship because I have to come in and see you—made me feel that strong pull to donate the money. When they ask you for a donation, if you don't give and you have an ongoing relationship with the institution, it does feel a little distorted."

Equity Concerns

Other narratives focus on equity concerns, including concerns that patients who donate will receive more (or better) care or services compared to patients who do not donate. Leslie Matthews expresses the belief that offering differing levels of care would be "highly unethical and against our mission as care providers." According to Matthews, "every patient should be treated with the same level of care, courtesy, and respect." Michelle A. Burack agrees and expresses disappointment when she learns that an institution has expedited access to COVID-19 vaccines for wealthy donors.

Some authors report experiencing no requests by donors for care or services that could raise equity concerns. As reported by James Malone, "I understand there has been some criticism of some grateful patient work related to expected favors or pressures to accommodate donors. I can attest that I have never experienced that in my time working with our foundation." Malone further shares: "I know there are times when donor requests come to our foundations and those professionals are trained and equipped to respond appropriately. I think sometimes that's related to navigating what can be a complex healthcare system and the frustrations that arise from that." Other authors share their fortune in not feeling institutional pressure to treat donor patients better than non-donor patients. For example, Joel S. Perlmutter feels fortunate that his institution did not place any pressure on him to give special treatment to donors.

Still other authors explain how donor patients do sometimes make special requests, including requests for urgent visits. Sometimes these requests can be accommodated by natural circumstances, such as another patient's cancelation that occurs close in time to the donor's request. Brent R. Carr experienced one such situation: "There is a plea [by the grateful patient] for an urgent visit. No availabilities exist for several weeks, though urgent, this is no imminent emergency. Our conscientious clinic manager, the same who is aware of the initial personalized check, is scouring the schedule for openings and asks if a clinic afternoon should be cleared. Before any such discussion can occur, a

patient cancelation leads to an opening within 48 hours of that plea." After his expedited appointment, Carr's grateful patient expressed gratitude for being seen on short notice by placing an envelope thick with money on Carr's desk.

Health Information Confidentiality Concerns

Some authors recognize that grateful patient fundraising can raise health information confidentiality concerns. As background, the federal HIPAA Privacy Rule permits a covered health care provider, such as a hospital, to use and disclose certain protected health information (PHI) for the hospital's own fundraising activities (Code of Federal Regulations, 2013a). The specific PHI that can be used or disclosed by a covered provider for fundraising has changed over time. Between 2003 (the HIPAA compliance date for most covered entities) and 2013, the federal Department of Health and Human Services (HHS) only permitted covered providers to internally use (or disclose to a business associate or institutionally related foundation) patient demographic information and dates of health care received (Code of Federal Regulations, 2013a). Between 2003 and 2013, then, it would be legal for a covered hospital's foundation to search an electronic records system for patients who live in wealthy zip codes and to send those patients fundraising communications, even if those patients had not given their prior written authorization. Searching by zip code was legal because a zip code is a type of demographic information. It would not have been legal between 2003 and 2013, however, for a covered hospital to search for patients treated by a particular physician (*e.g.*, Dr. Jones) or patients who were treated in a particular department (*e.g.*, oncology) unless such patients had given their prior written authorization. At that time, the name of the treating physician and the patient's department of service were beyond the scope of information permitted by HHS to be used for fundraising purposes without prior patient authorization.

Since 2013, however, HHS has allowed a broader range of PHI to be used and disclosed by a covered entity for its own fundraising purposes. This broader range of information includes demographic information, dates of health care provided to an individual, department of service information, treating physician, outcome information, and insurance status (Code of Federal Regulations, 2013b). As a result, it is legal today for covered hospitals to search their records systems for patients treated by particular physicians or for patients treated in particular departments and to send those patients targeted communications seeking funds for the treating physicians' research or for the specified departments' needs.

Some authors recognize that grateful patient fundraising can raise health information concerns under the HIPAA Privacy Rule provisions described above. Leslie Matthews, for example, explains that he initially felt that talking to a patient about a philanthropic investment could constitute a HIPAA violation. One narrative reveals distress when the physician learns that her patients can be targeted by a hospital for fundraising communications without the physician's knowledge or assent. As explained by Michelle A. Burack, "I sent an email to the advancement office. 'Can you please clarify—are our patients being targeted for donations?' I was informed that legislation passed the previous year made it possible for the advancement office to view the provider's name and department associated with a patient's most recent visit, and thereby use that information to send more targeted requests for donations." Burack explains how this made her feel: "I was distressed that the sacred space of trust that I so carefully cultivated with each patient was being breached by the institution without my knowledge or assent."

Wealth Screening Practices; Non-Monetary Donations

The narratives reveal a variety of efforts and opinions relating to wealth screening, which is the practice of searching publicly available records to identify current or prospective patients that might have the financial means to donate. Some narratives show how wealth screening works in practice. As

explained by Ahmet Hoke, "With Mrs. Jones, the process has played out as follows: She was first identified by development, via publicly available information, as a patient with the financial capacity and potential inclination to make a gift. My development officer, whom I'll call Mary, used various open-access data to generate a picture of this person, her background and interests, what she cares about, her giving history, and her possible further philanthropy." Other narratives illustrate physician non-involvement in wealth screening. Kenneth R. Adler explains: "I never reviewed wealth-screening reports (though I was invited to do so) . . ."

Still other narratives urge the development community to move away from wealth screening. Reshma Jagsi takes this position, reasoning that, "Abandoning these practices would make the benefits of altruism available to all and promote our institutions' worthy missions. Instead of focusing on those with substantial financial means, development officers should be encouraged to build relationships with all patients who wish to help the institution serve its mission—including those who cannot donate money but are willing to help in other ways." Jagsi lists several ways in which non-wealthy grateful patients can give back, including by sharing their stories and offering their perspectives regarding what the community needs from the institution.

Leslie Matthews agrees with Jagsi that giving can take shape in a variety of ways, including through volunteerism, sharing a story, or making a philanthropic investment. Brendan D. Curti also respects the non-monetary ways in which his patients demonstrate their gratitude, including by "participating in clinical trials, serving as volunteer educators and advocates, and humbling us with questions that sometimes lead to important discoveries." Kenneth R. Adler agrees, sharing many gracious forms of non-monetary donation: "Over the years, we received hundreds of cards, flowers, and home-baked sweets. One gardener showed up every summer with a delivery of giant eggplants, tomatoes, and peppers from her prolific garden. An astronaut sent me a photo of New Jersey from space. Artists arrived at appointments bearing watercolor paintings, and once, a small carving of a seagull. One time I even received Holy Water from Lourdes and was implored to share it with others. With each gift, each person in my care showed me a bit of him or herself that I wouldn't have otherwise seen."

Means of Minimizing Ethical Concerns

Several of the narratives identify ways in which ethical concerns associated with grateful patient fundraising can be minimized. Separating donation discussions from active treatment is one way. Reshma Jagsi explains how this can be done through careful communication with a grateful patient: "Right now, I think our main priority is on getting you the radiation therapy you need. Let's focus on that now, and we can talk about this [development] handout at some later time if you'd like when we've got the plan for care working well." Ahmet Hoke concurs with Jagsi that grateful patient discussions should be conducted at times that are sensitive to patients' health, well-being, and comfort and that such discussions should not be conducted during active treatment phases.

Several authors recommend physician referral to an institutionally-related foundation rather than physician initiation or physician involvement in the direct solicitation of patients. Michelle A. Burack shares: "As the years passed and my reputation as a local expert in my field became more widely recognized, I was asked to meet with two people from the advancement office to discuss direct face-to-face solicitation of donations from specific wealthy patients in my practice. I refused, saying I would happily facilitate a patient-initiated request but would never initiate the ask. Other authors agree with Burack. Jon A. Kobashigawa explains: "I generally don't do a hard ask, but rather I try to paint a picture of what's possible with continued support. If a patient expresses an interest, I will suggest connecting them with our Development team, who are there to work with the patient to find the most meaningful opportunity for them to give back." Brendan D. Curti agrees with Burack and Kobashigawa: "If they ask how they can support the research, I let them know that there are

brochures in the lobby or ask if they would like us to have a member of our foundation call them." Curti further explains: "To maintain my role as healer and teacher, I never participate in any solicitations or discussions with donors about potential gifts—though I may participate in reporting out to donors the impact of their giving." Joel Perlmutter also shares this opinion: "[I]f a patient and family raises the question of support, I refer them to the development office."

Conclusion

Grateful patient fundraising serves an important role in health care philanthropy but those involved must adhere to the ethical guidelines that govern physician involvement in grateful patient fundraising. The ethical concerns include conflicted physician decision making, injustices in health care resource allocation, financial exploitation, and privacy concerns (Tovino, 2014). As we see in these narratives, many physicians have successfully navigated grateful patient fundraising through proper guidance provided by their institutions and by working with or referring patients to their development office.

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Commentary
Grateful Patient Fundraising and the Unconscious Bias

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Abstract. This commentary discusses twelve stories in which physicians describe how they have been impacted, for better or worse, by Grateful Patient Fundraising (GPFR). There are clearly a vast array of feelings about this topic in the narratives, which include not only the often-discussed ethical dilemmas on the topic, but also how training and implementation of such programs can enhance or diminish relationships between the patient and their healthcare provider, the healthcare provider and their institution, or in at least one case, the patient and the institution. This commentary seeks to explore the pros and cons of GPFR, a necessity in research fundraising, and how some institutions are making this work. Ultimately each provider must find the balance within themselves on how to proceed with this topic. These narratives explore the authors' various opinions about GPFR.

Keywords. Unconscious Bias, Grateful Patient Fundraising (GPFR), Philanthropy, Affluence, Bioethics, Narratives

Authors' Note. The International Foundation for Gastrointestinal Disorders (IFFGD) was founded in 1991 by one person struggling with the challenges of living with chronic GI disorders. As an international nonprofit, our mission is to inform, assist and support people affected by GI disorders. For over thirty years, we have worked with patients, families, healthcare providers, researchers, employers, regulators, and others to broaden the understanding of GI disorders, support and encourage research, and improve digestive health in adults and children.

Introduction

Programs such as Grateful patient fundraising (GPFR) are development initiatives created to help clinicians and healthcare institutions secure funding through donations from grateful patients (Collins et al., 2018). This type of program is designed to foster a culture of gratitude by targeting the altruistic nature in humans. Altruism is an innate human instinct to benefit the welfare of others. This instinctual trait comes from an evolutionary history of needing to protect and support friends or family members from danger. Anne Frank

said, "No one has ever become poor by giving," meaning that people can experience unexpected gains from benevolence and goodwill. Even intrinsic benefits such as happiness and selflessness can impact patients whose outcomes were not always positive, such as those who may have lost a loved one. In Lauren Draper's narrative, we see that donations, albeit provided as a coping technique, can foster peace and a sense of comfort to families. James Malone describes how one of the most important lessons he learned from participating in grateful patient conversations is "how important this is for people's healing process—whether they are having a good outcome or not." This philanthropic altruism has helped fund healthcare institutions for years and is the key to strengthening an organization's performance.

However, the question raised in many of the narratives are not concerning the surprise unsolicited gifts from a grateful patient to a healthcare institution but rather the cultivation of wealthy individuals who are identified and then led down a path to give large donations by trained individuals in the institution's development office. It is estimated that each year American healthcare institutions alone receive over $5 billion in charitable donations through grateful patient fundraising (DonorSearch, 2015). While philanthropy is a necessary source of support for healthcare institutions, questions remain over the ethical dilemma and burden it can have on the doctor-patient relationship and the relationship of the physician with the healthcare institution itself. Will the patient expect preferential treatment in the future? Will the funds be used for what the donor intended? Will other physicians not working to get these large donations have equal opportunities at the institution based on merit and not their ability to fundraise? In addition, if the only opportunities for contributions are monetary, those who are indeed grateful but lack the financial means may not be given the opportunity to contribute, making the system non-inclusive and thus adding to the already tenuous ethical dilemma. Are we building a program to help grateful patients help others or simply targeting the wealthy patients in the system to fund building and research projects? The narratives raise these questions while demonstrating the benefit of GPFR to institutions, physicians, and the grateful patient. It is clear that a well-thought-out plan with transparency, education, and training yields the best results for all involved.

A Culture of Gratitude

Gratitude and appreciation can be expressed in countless ways. Many studies show that expressing gratitude is directly linked to greater happiness. It's no surprise that patients feel obligated to give back and show their appreciation for the excellent care they or a loved one received. According to a 2016 U.S Trust survey, 39 percent of surveyed donors said that "personal satisfaction, fulfillment, and enjoyment" was their top motivating factor for donating (Reading Partners, 2017). Grateful patient fundraising provides patients and their family members the opportunity to help and support other families struggling with similar situations. When you look at it from this lens, it seems there can be no problems with soliciting patients for donations, because it essentially benefits both groups.

Fundraising doesn't always allow for the less affluent demographic to show their appreciation. In one narrative, Reshma Jagsi mentions that non-monetary gifts are still an important contribution to the philanthropic mission, and help address equity concerns. If a culture of gratitude is the ultimate goal, then providing alternative methods of giving back could allow those individuals to feel that same level of satisfaction. Giving every patient this opportunity is not only more inclusive, but it can address the health disparities already happening across the world today. Kenneth Adler describes the many thoughtful gifts he has received over the years, including cards, flowers, baked goods, fresh vegetables from a grateful patient's garden, and other unique items. Brendan D. Curti says, "We also respect the many non-monetary ways our patients contribute by participating in clinical trials, serving as volunteer educators and advocates, and humbling us with questions that sometimes lead to important discoveries." Institutions should recognize the opportunity for grateful patients to give in

other non-monetary ways and cultivate this type of giving in the same way they do financial gifts.

Health Information, Privacy and HIPAA

New patients fill out paperwork identifying demographic information, including their annual income, level of education, and medical history. This information, which most would consider personal, is used by healthcare institutions to build their philanthropic community. Modifications in 2013 to the HIPAA Privacy, Security, and Enforcement Rules allow entities to use or disclose an individual's protected health information (PHI), without their permission, for fundraising purposes (Code of Federal Regulations, 2013). Health information that is legal to use includes demographics, date(s) of service, health insurance status, treating physician information, and the outcome of treatment (Richner & Schrems Penate, 2015). Ahmet Hoke mentions in his narrative that a development team member used "open-access data" to learn more about a patient's background, interests, and giving history. In this particular instance, Hoke was notified before meeting the patient that "she was an avid philanthropist" who had not yet given to the institution. The development officer used data from the intake forms filled out before the first appointment combined with publicly available information to target the patient for large donations. In fact, it's not uncommon for development teams to use alternative means such as social media to obtain data that paint a more detailed picture of the patient. Even though this is public data, some patients may feel that using this information for development purposes is intrusive and an invasion of their privacy.

Preferential Treatment

It is well known that those who have power and money benefit. Recently a hospital in Seattle was in the media for providing COVID-19 vaccines to their board members and donors ahead of immunocompromised patients (Bynum et al., 2021). Michelle A. Burack's narrative includes correspondence from one of her grateful patients, in which she asks the patient's opinion about a similar or perhaps the same news story just mentioned. Burack wonders if the patient felt donating would change their quality of care. The patient replies, "It actually happened. So there you go." We see this type of preferential treatment all the time, and it may give the impression that donors are put into a "VIP" category even in the healthcare setting, where reciprocity for their donation is expected. We see an example of this again in Carr's narrative when a donor needs an urgent appointment. The clinic manager—aware of the patient's financial gift—feels obliged to ensure the grateful patient gets an appointment. She asks if they should make room in the schedule just as a cancelation leads to an opening, and no decision has to be made on the matter.

Everyone has biases, and it's not always a bad thing. However, if these biases are not recognized or addressed, it can lead to poor decision-making at work, at home, or in relationships (Steinhauser, 2020). We call this an unconscious, or implicit, bias. According to the Kirwan Institute, implicit bias is "an attitude or stereotype that affects our understanding, actions, and decisions in an unconscious manner" (2012). These types of biases can be found in classrooms, courtrooms, and in this case, hospitals. One example of this can be found in a 2012 study where pediatric physicians were more likely to prescribe painkillers to white patients as opposed to black (The Kirwan Institute, 2012).

If physicians become aware of which patients are wealthy donors, pressure to make those patients' experiences as pain- and error-free as possible can lead to more successful treatment. However, presumably spending more time making sure one patient's care is exceptional can lead to another patient's care being downgraded. It leaves the question of whether patients can truly be treated with the same level of thought and care if this implicit bias exists. In a 2020 survey regarding the role of physicians in the encouragement of patient donations, 83% of individuals believe that having these philanthropic conversations with patients may interfere

with the patient-physician relationship. However, in this same survey, 50% of people also indicated that it would be acceptable for a hospital to provide things like nicer hospital rooms to a hypothetical patient who could provide a charitable donation of $1 million (Jagsi et al., 2020), thus highlighting the complexity of this issue and begging the question whether it is ethical to allow such practices. One thing clear in these narratives is the feeling that preferential treatment erodes a trusting patient-physician relationship and crosses a bioethical line in providing every individual with the same level of care and respect. Unfortunately, the authors of these narratives do not agree about whether this *is* or *is not* happening today in the hospitals they serve.

It is also important to consider the patient's viewpoint on the issue of preferential treatment. If the impression is given that preferential treatment will be received, it begs the question: Are donors grateful for the care received or afraid not to receive superior treatment? We are reminded again of Burack's patient, who hints that she believed there was a possibility of receiving extra TLC if you are flagged as a donor.

Doctor Involvement in Solicitation

It's essential for institutions to have development teams that facilitate philanthropic communication with patients. However, it is not uncommon for these teams to encourage physicians and other medical staff to use their relationship with their patients to determine the likelihood of a contribution in the future. We can see a contrast in opinion regarding physician involvement with charitable investments within these narratives. Some authors feel as though it "undermines the foundations of integrity they aspire to uphold" (Burack), and, similarly, others felt that "having these conversations felt like a breach in the doctor-patient relationship, unethical, and a violation of HIPAA." Interestingly, when effective training has been provided, the mindset of some of these physicians shifted into viewing this involvement as rewarding and something that "enhances provider wellbeing and increases patient satisfaction" [Matthews and Murray]. We also see the importance of this training within one narrative where a generous donation was given directly to the physician for enhancements in their field [Carr]. Internal convictions made it difficult for the physician to accept the gift and efforts to direct this donor to the hospital's development team were met with reluctance. The overall response to the donation may have been different if adequate training had been provided and could have opened doors for additional monies in the future. Providing training programs may help comfort the physicians involved and ensure these interactions stay within HIPAA guidelines and remain ethically sound.

Three of the narratives (Matthews and Murray, Hoke, Malone) gave details on their institution's training programs for physicians around grateful patient giving. Within these examples, it is clear the physicians themselves feel satisfaction and fulfillment in the opportunity to assist their patients with the ability to share their gratitude. Malone wrote, "being willing and able to respond to their expressions of gratitude is another way to show that we are committed to going above and beyond their expectations in their overall care." In these writings, the institutions work hard to implement successful programs to educate physicians and implement policies to make the experience ethically sound and seamless for the physicians involved. One institution went as far as to hold a summit to better understand the ethical dilemmas and how to navigate the process of grateful patient philanthropy legally and ethically (Hoke). It is clear that these healthcare providers feel strongly that they are contributing to the patient's wellbeing first and foremost and in doing so, are able to receive funds to achieve more in their research to help others. This suggests that the physician's mindset, the training they receive on how to handle these situations, and the transparency around the process influence the success of grateful patient philanthropic programs.

Accountability and Donor Transparency

For grateful patient programs to be effective, there must be accountability through donor transparency.

It is essential to show donors good stewardship and inform them of the results of their generosity. In doing so, patients will understand the value of their contribution and how it benefited others, hopefully encouraging future donations.

Transparency is also important within the workplace. It creates a more trusting relationship between the physicians and institutions and, in turn, generates a positive working environment (National Council of Nonprofits, 2021). However, when not implemented effectively, fundraising efforts can hinder the relationship between physicians and institutions and between the patient and physician. In one specific case, a patient graciously donated to help advance their physician's research but unfortunately, it cannot be confirmed if their donation was allocated in the way the patient had intended (Burack). In fact, when the physician later petitioned to receive funding for research that could have made her more clinically effective, the administration conveyed that funding was not available. This contributed to a sense of betrayal and the question of whether being more complicit in soliciting patients could have helped the physician's career further evolve. It also seemed to be a driving factor in the physician's resignation and what's more, their grateful patient lost a valued and trusting doctor. When donor transparency is not disclosed, the institution's integrity is jeopardized, as is the environment the gift was intended to support or advance.

Conclusion

These narratives show how GPFR is being handled today in several hospital systems. It is clear that while most seem to be utilizing development offices to do this type of fundraising, not all are achieving the highest level of physician satisfaction in doing so. In the narratives that focus on educating the physician and working with the development team to solicit donations, it is clear that the physicians felt greater satisfaction and genuinely believed that they were doing what was in the best interest of the patients and their loved ones. Unfortunately, the physicians did not have the same feelings in the narratives where this training and clear transparency were not part of the process.

Fundraising for research is becoming increasingly important, and institutions are finding that donations from grateful patients provide a wonderful way to fill budget shortfalls, enhance the patient care experience, and provide physicians with funding to advance their research (Prokopetz & Lehmann, 2014). However, there is much to consider in the ethical dilemmas around GPFR. Moving forward, institutions must consider the impact these programs will have on the patient-physician relationship and balance this with the need to fundraise for their programs. Surely, a sound training program based on ethical standards and a strong institution-physician partnership will go a long way in helping ease the strains felt in these narratives.

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Commentary

Grateful Patient Philanthropy: A Challenge to Organizational Ethics

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Abstract. An examination of organization development in health care reveals a pattern of increasing reliance of academic medical centers toward new sources of revenue in support of operations. This trend is partly in response to the reduction of traditional funding sources such as public appropriations and tuition. Clinical income from faculty earnings and hospital transfer payments have supplanted heritage funding sources and are now predominantly institutional transactions rather than physician-patient interactions. Grateful patient philanthropy can be viewed as moving toward transactional status, with challenging ethical questions for the involved physician and patient as institutional control increases.

Keywords. Narratives, Grateful Patient Fundraising, Physician-Patient Relationship

Introduction

The institutionalization of grateful patient fundraising programs has opened a new vein of revenue for academic medicine and its practitioners in the last two decades. Wright and colleagues (2013) state that "Grateful patient philanthropy is an essential part of keeping academic medical centers (AMC) moving forward." The implication is that a once tangential activity is now a mainstream component of medical school financial health. One may learn lessons from the institutionalization of patient care generated revenues in academic medicine compared to recent developments in philanthropy in general and grateful patient programs in particular.

Paul Starr (1982) notes that nineteenth-century U.S. Hospitals were often reliant on charitable donations for operating income, but in the instance of the Pennsylvania Hospital and other traditional donor established hospitals, these funds were inadequate to cover the cost of care and required

supplementation from patient payments. Charles Rosenberg (1987) noted the difference between U.S. and historic hospitals of longer standing in the U.K. as requiring patient payments, albeit in a minority of instances. Both authors agree that while hospitals might receive payment for services, physicians were expected to deliver their services to the indigent as an act of charity.

As payment for services rendered became more widely accepted in the later nineteenth century, philanthropy as a revenue source was increasingly the domain of select private institutions and religious organizations. A movement away from philanthropy for operating purposes occurred as patients paid either directly or through a more steady and preferred source with the advent of third party insurance in the twentieth century.

In the institutional sector, philanthropy was increasingly redirected toward capital project support. These funds were more often than not comprised of major naming gifts from corporate or individual donors and directed to physical structures. Smaller gifts from alumni and others in the immediate community were welcomed but often attained with little organized effort other than periodic capital campaigns (Garland, 1988).

Physician payment evolved in a separate but parallel course from institutional payment in which a "grateful patient" component was an essential part of the physician's remuneration. Through the nineteenth century, an unstructured payment approach prevailed in which indigent patients would be treated through the charity of the physician, but patients of means would be expected to pay accordingly. Often cited as "Robin Hood" pricing, taking from the rich and giving to the poor, was a strangely ethical, though totally informal approach to paying for professional services and distributing their availability through society (Moreno, 1990). In a sense, this carried on the Roman tradition of "honoraria" in which classical physicians "were paid with a gift determined by the satisfaction of the employer or client" (Jonsen, 2000).

The movement from a barter economy to a rationalized system of payment characterized the development of physician payment in the twentieth century. The American Medical Association supported the approach of fee-for-service medicine as ethically superior by assuring the direct economic obligation of the physician to act "in the patient's best interest" (Baker, 2013).

Indeed many of the authors of these NIB narratives mention an initial apprehension to engage in grateful patient fundraising out of concern for the physician-patient relationship. Joel S. Perlmutter states, "I am somewhat reluctant to initiate these discussions [. . .] since I do not want that to intrude on the patient-physician relationship." Ahmet Hoke says he feels "fortunate to work for a medical center that performs grateful patient fundraising (GPFR) in a professional, ethically sound way [. . .] allowing the physician-patient relationship to remain focused first and foremost on the patient's health and well-being." Hoke ascertains that when done in a way that preserves boundaries, grateful patient fundraising can strengthen the physician-patient relationship.

With the advent of the first Blue Shield plan in 1939, third party payment for physician services accelerated as employers increasingly added this benefit to workers during the wage control era of World War II. Physician payment based on principles of "usual, customary, and reasonable" standardized and eroded the historic informal structure of physician payment. This trend culminated in the enactment in 1965 of Medicare and Medicaid and the removal of a significant portion of the populace from the ranks of the medically impoverished. The net effect was to minimize the earlier custom of differential payment for physician services as patients became used to the idea of fee-for-service that was often "covered" by insurance.

No Longer Threadbare or Genteel

The impact of these changes in payment found their way to academic medicine to a degree few had anticipated. In a widely cited 1981 New England Journal of Medicine essay, Robert Petersdorf (soon to become President of the Association of American Medical Colleges), observed the changing landscape for academic physician faculty:

> His expectations were to do research and teach and take care of patients only peripherally. He had few private patients. In fact, most patients with whom he came into contact were ward patients who received care primarily from house staff.
>
> His research was carried out on a small scale and supported to a great extent by private philanthropy. There was no competition either for dollars or for priority scores. Academic departments were small and collegial, and life was more like that of a professor of English or philosophy than like that of a practitioner (Petersdorf, 1981).

Petersdorf was commenting upon the rise in faculty practice and institutional transfer revenue to medical schools that eventually dwarfed traditional funding sources of tuition, public appropriation support, endowment income, and research funding. By the time of the 1996 AAMC Report "The Financing of Medical Schools," clinical income from faculty earnings and hospital transfer payments had exceeded the four traditional revenue sources in total at the average medical school (Association of American Medical Colleges, 1996).

Interestingly philanthropy is not regarded as of sufficient magnitude to warrant a specific category of revenue for comparative analysis. The AAMC Task Force, chaired by David Korn, the former Dean of the Stanford University School of Medicine, is relatively dismissive of the impact of philanthropy on the medical education enterprise. The Report notes the following with regard to the import of gifts:

"Gifts to medical schools are characteristically restricted, sometimes to a broad area of application (heart disease, dementia), but more often to work on specific diseases or to support the scholarship of specific faculty" (Association of American Medical Colleges, 1996).

The 1996 AAMC Task Force concludes its work with 24 recommendations, emphasizing the increasing reliance of medical schools on practice-generated revenues while cautioning that this is probably not sustainable for the extended future. Events have demonstrated the continuation of an even greater dependence on clinical revenues, especially in public universities that witnessed substantial decreases in public appropriations. Against this backdrop, the development of new fund sources, including grateful patient philanthropy becomes of heightened interest.

What One Measures, One Gets

Clark Havighurst, (2004) the William Neal Reynolds Professor Emeritus of Law at Duke University, popularized the above statement as applied to institutional management. One of the most vivid examples of his mantra can be found in the move from near non-recognition of philanthropy as of relatively little importance to the academic enterprise to one warranting major institutional investment and monitoring.

In 1999 the AAMC initiated a web-based Annual Development Survey to measure the impact and costs of fundraising efforts on behalf of medical schools and owned or affiliate hospitals. By 2020, the AAMC Report identifies mean annual private institution funds raised of $111.5 million and $58.9 million by responding public institutions. It may be argued that only organizations placing a high value on fundraising (N=122, 56 private and 66 public) responded to the survey, resulting in artificially high results (Association of American Medical Colleges, 2021).

Clearly this attention reflects a major shift in the perceived value of fundraising, much as the 1980s and 90s saw the recognition of the importance of clinical sources of revenue and the organization of the AAMC Group on Faculty Practice in 1986. There is now an AAMC Development Leadership Committee that advises AAMC staff on the content of the annual survey. 56 of the institutions responding to a specific question report they "have access to conduct grateful patient fundraising efforts," while only 8 do not (Association of American Medical Colleges, 2021).

Indeed, the results have become a point of comparison across academic institutions. The University of Miami Miller School of Medicine reported in 2016 that its fundraising placed it number 11 among reporting medical schools with hospitals and health centers). To my personal astonishment, one of the

institutions ranked ahead of Miami in that report was the University of Wisconsin-Madison, which had not even tracked this metric at the level of the medical school when I served as its Associate Dean for Administration and Finance from 1992 to 1995.

When Does a Gift Become a Quota?

Much in the same way that physician fees became a subject of institutional budgeting that support current operations, is it possible that philanthropy will move in the same direction? After all, as Director of Administration and Finance at the University of California-San Francisco, I was once chastised by a prominent faculty surgeon for waiving a balance of $3.89 for the spouse of a university Regent at the request of our Chancellor. The surgeon in this case viewed the fee for his service as solely his product, and exclusively his to control. With over half of all physicians practicing in organized groups, such a disagreement would seem unrealistically quaint to most physicians, given the transfer of authority over financial issues and productivity standards such as RVUs to a central administrative entity.

The notion of a gift is in itself elusive. In his classic work "The Gift Relationship: From Human Blood to Social Policy" (1997), Richard Titmuss argued for "altruistic gifts" as ethically superior and ironically more efficient in realizing a social goal (enhanced blood donation) than a transactional approach. The narratives in this issue demonstrate a recurrent theme—the authors are concerned with avoiding coercive or exploitative relationships with patients who may be motivated by altruistic giving or who may expect preferential treatment after donating a financial gift. Brent R. Carr for one describes his uncertainty when a grateful patient hands him a check made out to him personally. He declines the check and refers the patient to the development office, though Carr says, "I did not energetically market the development office, not wanting to appear coercive or steer the choice." The patient later attempts to make another donation, this time placing an envelope with cash on the desk.

The American Medical Association Code of Medical Ethics addresses this concern in Standard 10.018, stating that "Donations play an important role in supporting and improving a community's health care. Physicians are encouraged to participate in fundraising and other solicitation activities while protecting the integrity of the patient-physician relationship, including patient privacy and confidentiality, and ensuring that all donations are fully voluntary" (Council on Ethical and Judicial Affairs, 2017). However, the AMA follows its opinion and seems generally favorable to fund development by opining that "The greater the separation between the request and the clinical encounter, the more acceptable the solicitation is likely to be" (Council on Ethical and Judicial Affairs, 2017).

The narratives obtained for this issue of Narrative Inquiry in Bioethics have displayed great sensitivity to the issues of potential coercion in obtaining grateful patient donations while cautioning that these donations do provide extra funding to provide research or patient care services otherwise unavailable through institutional budgets (See Perlmutter, Curti, Hoke, Draper, and Kobashigawa.) Of course, at one time this observation might have applied to the generation of professional fees before these sources were captured by bureaucratization and made part of the support of ongoing operations.

Nelson and Taylor (2022) identify the potential for donations that do not fit the Titmuss category of altruistic gifts and the need to provide ethical guidelines regarding their acceptance. Sanky and Appel (2020) propose in their article on "tainted largess" in medical school donations three tests of a gift before its acceptance. First, they suggest the need to scrutinize the donor's expressed views, actions, and conduct. Secondly, they ask what is the source of the donor's funding to exclude corrupt sources of funds but also money that exceeds the reasonable capability of the donor to make the gift. Third, what are the donor's motivations for giving?

These can be difficult assessments for the physician to make, and are a source of concern to the authors of our narratives in this issue. Author Reshma Jagsi has no questions about whether her patient who had just finished explaining how her "daily radiation treatments were going to pose a substantial financial burden to her family" could

afford to make a financial gift. The patient was handed a pamphlet about fundraising opportunities at the reception desk and asks Jagsi about it. Jagsi explains in her story, "I did not want to make her feel bad about her financial status. I did not want her to worry that her inability to donate would have any influence on my care for her. I wanted to maintain her trust."

Malinowski (1962) raised the question of the limits of a model of altruistic gifts, and other anthropologists have observed the functional exchange nature of gifts in promoting social harmony. The legend at the old Peter Bent Brigham Hospital in Boston that was passed on to new house officers suggested that Mr. Brigham had donated his fortune to establish the hospital bearing his name as restitution for his discovery that a pie had five quarters. The narratives in this issue reflect this dilemma and often site the involvement of professional development officers as a desirable solution to such difficult judgments.

Dr. Leslie Matthews co-authored a narrative with philanthropy colleague Leah Murray. They write, "Providers are encouraged to think of their philanthropy colleagues as an extension of the care team, where our philanthropy professionals can triage their gratitude and match them to the most appropriate opportunity."

Grateful Patient Donations as a Restoration of Relationship in the Physician-Patient Dynamic

In the contemporary world of increasingly corporatized and bureaucratized interactions between patients and physicians, the once highly personal interaction of the two on the payment of professional fees is now shrouded by back-office billing or collection personnel and the presence of third party payers that set the terms for payment. Ironically, the depersonalization of this aspect of the caregiving process is attractive to many physicians who prefer to leave this work to others. Younger physicians in particular find relief from this perceived burden as an attractive element of practice within an organizational setting.

Is it possible that the grateful patient gift is an attempt by the donor to reestablish the personal dimension by the patient into a world of increasingly sterile encounters? As noted previously, a gift may convey benefit to the giver of a nearly therapeutic character while not meeting the definition of an altruistic gift.

Conclusion: To Whose Benefit?

Academic medical institutions are increasingly reliant on grateful patient donations as a funding source. In the best case, these funds allow the organization and its physicians to head in new directions of patient care and research that would not be otherwise sustainable. As one looks at the history of grateful patient initiatives, this is the justification cited in the early days of such programs.

A cautionary parallel case exists in the realm of professional fee generation that has increasingly supplanted lost revenue from other sources, especially public appropriations. As pressure continues on these sources of operating funds, will grateful patient donations be increasingly captured to support operating expenses of the institution?

A public policy question is whether grateful patient donations address the shortfalls in the mission attainment of medical schools. At the level of policy, primary care and mental health are identified as glaring deficits in the U.S. health care system. The U.S. Health Resources and Services Administration (2019) identified a deficit of 13,758 primary care physicians and 6,100 psychiatrists in known provider shortage areas alone. While the missions of U.S. Schools of Medicine vary from research intensive schools to those with an avowedly community focus, these concerns are common to all.

Public health is another acknowledged shortage area that is under resourced (Watson, 2022). The current COVID-19 pandemic has increased public awareness of this vulnerability in the U.S. health care system, but funding for future academic initiatives in this area remain uncertain.

As one reviews the grateful patient narratives in this issue, a general theme emerges of patient gratitude for what might be considered tertiary

services associated with rescue medicine that are more in the realm of specialty care. As Wright and colleagues note (2013), ethical considerations of patient vulnerability typically enjoin psychiatrists from approaching patients for donations.

Management of chronic disease may not attract donors to the degree more dramatic interventions can attain. Research breakthroughs in primary care are more often generated through health services research rather than in basic science research that might generate a cure for a problematic disease.

Can ethical practices prevail in grateful patient philanthropy as institutional pressures for additional funds increase? The stories in this issue of Narrative Inquiry in Bioethics certainly give us hope. At the same time, we must remember Chaucer's Pardoner's cynical admonition, "Radix Malorum est Cupiditas" and maintain our organizational firewalls at full strength (1959).

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