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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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