EDITORIAL AND COMMENT

Family Caregivers and Physicians Caring for Cancer Patients: On-the-Job Training for All

Paul R Duberstein, PhD

Departments of Psychiatry and Family Medicine, University of Rochester Medical Center, Rochester, NY, USA.

J Gen Intern Med 29(9):1215-7

DOI: 10.1007/s11606-014-2936-4

© Society of General Internal Medicine 2014

I am writing from the bedside of a family member who recently underwent pancreaticoduodenectomy. After participating in two brief training sessions and watching nurses do their jobs, I learned how to administer total parenteral nutrition, flush a pancreatic drain, and handle other caregiving tasks. I am not alone. More than 40 million Americans serve as unpaid caregivers for a family member who is 50 years of age or older. Given the psychological burdens of caregiving and the need for on-the-job training, family-directed interventions have been mounted.¹

As Griffin et al.² (this issue) note, an “implicit assumption” of these interventions is that “the patient will also benefit.” The authors do not unpack these assumptions, but the credibility of their argument, and its relevance for clinical practice and policy, require the identification of plausible mechanisms. There are at least three. First, interventions might improve *communication and decision-making at the point-of-care*, thereby, for example, decreasing patient exposure to treatments that do more harm than good. Such was the case in a study³ that was excluded from the review because it was conducted outside the United States. In that study, an intervention for family members of patients dying in intensive care units both decreased patient exposure to futile treatments and improved caregiver bereavement outcomes. Second, caregivers might be taught *disease management skills* (e.g., pain, nutrition) that directly benefit the patient. Third, intervention-induced improvements in caregiver quality of life (QOL) could be transmitted to the patient via *psychological* processes (e.g., empathy, conditioning, social learning) that are facilitated by commonalities (due to genetics, homophily or living in a shared environment) between patient and caregiver. By virtue of the same psychological processes that account for increased physical resemblance among older spouses⁴ and increased caregiver morbidity after exposure to patient suffering,⁵ patients might benefit from improved caregiver quality of life.

Despite the presence of plausible mechanisms, the authors “found little evidence” that patients’ outcomes “were more

effectively addressed by a family-involved intervention.” Nonetheless, they encourage more research on this topic. Observing that all but two of the 27 trials were of poor or fair quality, they call for increased methodological rigor.

Rigor is needed, but so is greater stakeholder involvement in the research process. Community psychologists have long recognized that a project’s societal impact is proportional to the diversity of perspectives represented.⁶ Only recently has this principle earned the imprimatur of federal policy, with government agencies now requiring community-based participatory research and stakeholder involvement throughout the research process.⁶

As a caregiver, I can personally attest to the need for stakeholder involvement. Despite co-authoring a meta-analysis on caregiver interventions,¹ I had seriously underestimated the skills and knowledge required for effective caregiving. Patients, caregivers, physicians, nurses and other members of care teams have an insider’s understanding of cancer care and its aftermath that is unavailable to researchers with no first-hand cancer experience.

PHYSICIANS AND CAREGIVING RESEARCH

After a quick internet search, I was able to discern that a physician served as first author on only one of the 27 articles included in the review.² Given that physicians spend more time than social scientists interacting with cancer patients and their family caregivers, this authorship pattern might be viewed as a curiosity, but it is not a historical accident.

Caregiving is an ideal topic for scholars interested in the effects of stressors and changing life circumstances on well-being and health. Social scientists and nurses have dominated caregiving intervention research and the broader caregiving literature, uncovering caregiving’s upsides (e.g., benefit-finding), along with its darker and deadly consequences (e.g., elder abuse, domestic violence, murder-suicide⁷).

If this authorship pattern is interpreted to suggest that physicians have largely avoided the topic of caregiving, one must wonder why. The reason, I think, is *culture*. Informed by particular models of disease, payment, and science,⁸ medical

culture has historically placed disproportionate emphasis on biomedical cures for disease, while de-emphasizing the effects of disease and its (over) treatment on patients and families.⁹ Medical culture reinforces the physician's interest in pathophysiology more than it reinforces interest in psychosocial processes.⁸

FROM CURE IN THE CLINIC TO CARE AT HOME: CHANGING LABOR PATTERNS OF PATIENTS, CAREGIVERS AND PHYSICIANS

May et al.⁹ argue that the ongoing transition from "cure in the clinic to care at home" has had "the paradoxical effect of adding ...to the work of being sick" (pg. 486). Historically, family caregivers have provided mainly physical labor, assisting patients with activities of daily living, such as bathing, dressing, feeding, and toileting.

Increasingly, caregivers provide cognitive labor. Not only do these de facto members of the care team monitor symptoms, dispense medications, and accompany patients to medical appointments, but they also handle medical devices historically restricted to licensed clinicians. When the disease can no longer be kept at bay, and patients are unable to speak for themselves, physicians will ask caregivers about patients' preferences for life-prolonging treatments. Some caregivers know these preferences, but some can only guess. Guesswork is hard work.¹⁰

May et al.⁹ focused on the increased cognitive load on patients and caregivers, but the physician's cognitive burden has also increased. For the physician, the increased need to interact with caregivers about home care coincides with mounting pressure to shorten hospital stays, decrease rates of re-hospitalization, minimize the burden of treatments,⁹ maximize clinical outcomes, and increase patient satisfaction ratings. Just as caregivers are now providing a form of cognitive and emotional labor unknown to caregivers of previous generations, the cognitive and emotional¹¹ demands on today's physicians would be hardly recognizable to their forbearers. Burnout among physicians who care for seriously ill patients¹² and burden among family caregivers are both rooted, in part, in the type of work they have been asked, or demanded, to do. Mitigating these burdens will require the involvement of patients, caregivers, and physicians in psychosocial research. It will require culture change.

ON-THE-JOB TRAINING FOR ALL

"Healing,' Papa would tell me, 'is not a science, but the intuitive art of wooing Nature.'" So wrote W.H. Auden, a physician's son, in a poem following the death of his own physician.¹³ Mentorship, talking with other clinicians, and self-reflection enable physicians to refine the seemingly

intuitive empathic skills needed to respond to a patient's expression of frustration or to handle a caregiver's angry accusations.

Yet physicians require something more than empathic intuition to help patients and caregivers make decisions when the stakes are high, trade-offs plentiful, and outcomes uncertain. Framing prognostic information in a manner that maintains the right balance of optimism and pessimism at a particular moment or for a particular family requires sociocognitive skills and knowledge beyond empathy. The same is true of eliciting patient and caregiver priorities about starting chemotherapy treatment in the setting of multimorbidity and mild cognitive impairment or discontinuing third line chemotherapy due to poorly controlled diarrhea and lack of perceived effectiveness.

Knowledge of pathophysiology is required to develop biological treatments for disease. Similarly, it could be argued that some knowledge of the social and decision sciences is needed to effectively engage families in high-stakes decision-making. A more robust integration of the sociocognitive sciences into the medical curriculum might improve the quality of medical decision-making and medical care more generally.

On-the-job training, which is less formal than classroom education and less ad hoc than observing skilled mentors, might also be effective. Recognizing the unrelenting sociocognitive demands on all parties at the point-of-care, interventions have been mounted to improve disease management and decision-making.¹⁴ Whether directed at physicians (coaching, retreats) and/or patients and caregivers (coaching, question prompt lists, decision aids, interactive multimedia computer programs), these interventions presume that some patterns of interaction at the point-of-care are better than others.

Healing, according to the poet, might be an intuitive art, but point-of-care interventions are premised on the assumption that healing could be engendered by modifying patterns of interaction between patients, caregivers, and physicians. As decision scientist Herbert Simon¹⁵ put it, the intuition of experts "is nothing less and nothing more than recognition" of patterns. From this perspective, the intuitive art of healing could be engineered by research teams that have been re-constituted for 21st century science^{6,8} to create salutary interactions in care settings. In addition to improving patient outcomes, the involvement in "caregiving research" of physician and caregiver stakeholders with self-interest and insider knowledge might lead to reduced physician burnout and caregiver burden.

As a caregiver, I hope the on-the-job training I received from hospital-based and visiting nurses will influence my family member's outcomes. As a researcher, however, I am not surprised that the review² in this month's Journal yielded discouraging findings. It is hard enough to show that caregiver-directed interventions will improve caregiving outcomes, let alone patient outcomes. Clearly, Griffin et al. are right to call for more rigorous research. Opportunities

also abound for research on the mechanisms by which family-directed interventions improve patient outcomes. Beyond these refinements, greater stakeholder involvement in the research process, and the transition from cure in the clinic to care at home, represent exciting opportunities to develop novel point-of-care interventions inspired by the principle of on-the-job training for all.

Acknowledgements: I would like to thank Nancy L Talbot and Ronald M Epstein for their helpful comments.

Corresponding Author: Paul R Duberstein, PhD; Departments of Psychiatry and Family Medicine, University of Rochester Medical Center, Box PSYCH, 300 Crittenden Boulevard, Rochester, NY 14642, USA (e-mail: Paul_duberstein@urmc.rochester.edu).

REFERENCES

1. **Sorensen S, Pinquart M, Duberstein P.** How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist*. 2002;42(3):356–372.
2. Griffin JM, Meis LA, MacDonald R, et al. Effectiveness of family and caregiver interventions on patient outcomes in adults with cancer: A systematic review. *Journal of General Internal Medicine*. DOI: [10.1007/s11606-014-2873.2](https://doi.org/10.1007/s11606-014-2873.2).
3. **Lautrette A, Darmon M, Megarbane B, et al.** A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med*. 2007;356(5):469–478.
4. **Zajonc R, Adelman P, Murphy S, Niedenthal P.** Convergence in the physical appearance of spouses. *Motiv Emotion*. 1987;11(4):335–346.
5. **Monin JK, Schulz R.** Interpersonal effects of suffering in older adult caregiving relationships. *Psychol Aging*. 2009;24(3):681–695.
6. **Tebes JK, Thai ND, Matlin SL.** Twenty-first century science as a relational process: from Eureka! to team science and a place for community psychology. *Am J Community Psychol*. 2014;53(3–4):475–490.
7. **Malphurs JE, Cohen D.** A statewide case-control study of spousal homicide-suicide in older persons. *Am J Geriatr Psychiatry*. 2005;13(3):211–217.
8. **Engel GL.** How much longer must medicine's science be bound by a 17th-century world-view? *Psychother Psychosom*. 1992;57(1–2):3–16.
9. **May C, Montori VM, Mair FS.** We need minimally disruptive medicine. *BMJ*. 2009;339:485–487.
10. **Wendler D, Rid A.** Systematic review: the effect on surrogates of making treatment decisions for others. *Ann Intern Med*. 2011;154(5):336–346.
11. **Larson EB, Yao X.** Clinical empathy as emotional labor in the patient-physician relationship. *JAMA*. 2005;293(9):1100–1106.
12. **Shanafelt T, Dyrbye L.** Oncologist burnout: causes, consequences, and responses. *J Clin Oncol*. 2012;30(11):1235–1241.
13. Auden WH. The art of healing (In memoriam David Protech, M.D.). *The New Yorker*. September 27, 1969, pg. 38.
14. **Laidsaar-Powell RC, Butow PN, Bu S, et al.** Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns*. 2013;91(1):3–13.
15. Simon HA. The scientist as problem solver. In: Klahr D, Kotovsky K, eds. *Complex information processing: The impact of Herbert A. Simon*. Hillsdale, NJ: Lawrence Erlbaum Associates; 1989, pp. 375–399.