

Published in final edited form as:

Am J Bioeth. 2022 July; 22(7): 86–87. doi:10.1080/15265161.2022.2075961.

A Case of Patient Abandonment, or an Abandonment of Patients?

Jason Karlawish, MD,

Department of Medicine, Department of Medical Ethics and Health Policy, Department of Neurology, University of Pennsylvania Perelman School of Medicine

Andrew Peterson, PhD,

Department of Philosophy, Institute for Philosophy and Public Policy, George Mason University

Justin Clapp, PhD, MPH,

Department of Anesthesiology and Critical Care, University of Pennsylvania Perelman School of Medicine

Emily A. Largent, JD, PhD, RN

Department of Medical Ethics and Health Policy, University of Pennsylvania Perelman School of Medicine

What's the ethical problem here?

First—before you define the dilemma, parse out principles, or vocalize about virtues—consider what caused this case.

The COVID-19 pandemic has challenged us all, but particularly caregivers and the people they care for. In the United States, the backbone of the system of long-term care for the millions of persons like Benjamin is their families. When the pandemic hit, these families were cut off from critical services and supports, often struggling in isolation. Staffing shortages and visitor restrictions in long-term care facilities separated residents from family caregivers and contributed to malnutrition, delirium, and worsening disabilities; many died. As adult day activity programs closed and health aides kept away from homes, families took on additional responsibilities without respite. As demands on caregivers exceeded reasonable limits, caregivers' lives were consumed and persons living with dementia suffered.

The pandemic has been an awful natural experiment in what happens when care is delayed or taken away. For persons living with dementia and their caregivers, COVID-19 stressed a system of care that is, in truth, a non-system. Even before the pandemic, they struggled to obtain care. At least Benjamin had a diagnosis. Part of the vast problem of Alzheimer's disease is the struggle to obtain even a diagnosis and, after that, to negotiate our nation's byzantine pay-as-you-go system of long-term care services and supports.

Karlawish et al. Page 2

Out of this vortex created by this non-system and a massive public health crisis came awful stories like Gavon's and his parents'. Customers stayed home, and Gavon lost his retail job. As care went virtual, Benjamin and Trudy likely delayed doctor's visits or cancelled them; they managed as best they could, if at all, with telemedicine. Alone together, their problems multiplied, until Gavon became desperate. Gavon did what he did. The emergency department (ED) staff who requested the consultation called it a case of "abandonment." Amongst themselves, in the privacy of the break room, they probably used stronger words. But Gavon and his parents have arguably all been abandoned.

Ethics consultations are often cases presenting tricky conundrums that require analytic hairsplitting. Not this case. In fact, this ethics case is not an ethics case. The ethically appropriate step is therefore to call off the ethics consult and call in care consultants.

But what care?

The ED ought to consult with social work and geriatric medicine to help figure out why Benjamin didn't receive adequate care. These consults will examine whether Trudy and Gavon received education and training in caregiving. Did they have someone to call when they needed help? Did they know how to assist Benjamin with activities of daily living, how to maximize mobility and perform proper skin care? Did they need help applying for Medicaid or understanding Benjamin's Medicare benefits?

Perhaps these consultants will discover horrible things: that Trudy and Gavon have rejected multiple offers for care; that they've mismanaged Benjamin's resources, even exploited him; that this abandonment in the ED is the sad denouement of bad decisions and persistent, even willful neglect. Those would be ethical, even criminal, matters. That would be an appropriate time to call the ethicist, and perhaps also adult protective services, to the bedside.

But we don't know these things. Until proven otherwise, it's best to assume that Trudy and Gavon have the best of intentions to help Benjamin, their husband and father. Ordering an ethics consult casts a judgment over his caregivers that they've intentionally neglected Benjamin and are indifferent to his wellbeing. Calling an ethics consult is more likely to sow distrust than to facilitate good care. The ethicist, then, should help the requestor appreciate the conditions that led to Benjamin's sad arrival in the ED. Seeing these conditions differently will help identify whom to consult. The ethicist can offer to assist, if needed, once more information is gathered.

Benjamin, Trudy, and Gavon are refugees in search of help. They're like Ukranians wandering through Poland's forests, central Americans braving our hostile southern border, or the unnamed woman who set her infant in a small papyrus boat amongst the reeds of the Nile riverbank in hope that her infant son would be cared for, not killed, by the Pharaoh. All were suffering because they lived in systems that created difficult conditions and forced desperate choices. It is no wonder that Benjamin arrived in the ED.

This case is not about Gavon or his desperate cry for help. It's about us. This is a case about our duty to help Benjamin and his caregivers restore their home into a caring place

Karlawish et al. Page 3

or, perhaps, find him a new home where he can be cared for. It's a case that calls upon our humanity, compassion, and humility to help those in need.

Funding:

Dr. Karlawish is supported by the National Institute on Aging (P30-AG-010124). Dr. Peterson is supported by the National Institute on Aging (R21AG069805). Dr. Clapp is supported by the National Institute on Aging (U54 AG 063546). Dr. Largent is supported by the National Institute on Aging (K01-AG064123) and a Greenwall Faculty Scholar Award.