



Guardianships: Can Guardians for Adult Patients Assist Health Care Professionals to Provide Coordinated Care?

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Purpose:

To decrease the potential for miscommunication and difficulty in providing care to incapacitated patients who have a court-appointed guardian.

We are evaluating current Pennsylvania Law on the limits of healthcare decision-making for court-appointed guardians, ways in which guardians are authorized to make decisions, and how a shared understanding of medical and legal concepts could assist healthcare and end-of-life decision-making for incapacitated patients.

A 2014 Elder Law Task Force in Pennsylvania found that education for guardians is needed.¹ One area of education is to improve decision making on when to withhold medical treatment.² The number of incapacitated people is increasing nationally making this a more relevant issue.³

As a result of recommendations from this task force, under a 2019 Penn State Strategic Initiative Seed Grant focused on Constituent Outreach and Engagement, that brings together the Colleges of Medicine, Nursing, Law, and Behavioral Sciences and the Pennsylvania Court system, we are in the process of creating online learning modules for guardians. We can expand this task to assist in education of medical professionals.

Research Design:

A review of cutting-edge Pennsylvania law and focus group interviews with guardians, judges, lawyers, and healthcare providers regarding healthcare decision-making.

Typically a guardian will be appointed by the court when a person has a major neurocognitive disorder which reduces or removes the person’s ability to make decisions recognized under the law.⁴

The project reveals gaps and challenges under current law governing guardians while they are making healthcare and end-of-life decisions for patients who cannot speak for themselves.⁵ One such challenge is whether guardians can make a decision to discontinue life-sustaining treatment because the guardian believes this decision reflects the values and wishes of the patient, or whether current law prohibits such a guardian decision, defaulting to life-preserving measures, in the absence of a court order.⁶ Another challenge is the guardian’s inability to consent to biomedical or behavioral experimental procedures for an incapacitated person without explicit court approval.⁷

Our project is designed to assist in identifying better practices for medical personnel when working with guardians.

One focus of this project is the interaction between court-appointed guardians for cancer patients and medical teams, such as cancer navigators, when evaluating healthcare and end-of-life decisions.

We will share online learning modules, currently under development, for education of guardians in their legal obligations and discuss emerging best practices in working with medical personnel. Our project follows an 18-month schedule beginning April 1, 2019.

Expected Impact:

Guardians have important roles to play in the delivery of care, including cancer care, when there is a permanent or temporary inability of the patient to communicate.⁸

Shared understanding of limitations on lawful authority among healthcare professionals, guardians, family members, and similar third-party decision-makers will reduce the potential for misunderstanding and delayed decision-making for patients who are unable to speak for themselves when undergoing treatment.⁹

Expanding the audience for the 2019 Strategic Initiative Grant project to include health care community professionals will better serve the interests of cancer patients and facilitate quality of all care in an integrated setting.

By expanding the audience of these educational modules, we anticipate improved care for incapacitated patients as a result of enhanced relations and communication between guardians and medical professionals.

References:

1. The Supreme Court of Pennsylvania, *Report and Recommendations of the Elder Law Task Force*, at 24, 237, 239, 240 (November 2014).
2. The Supreme Court of Pennsylvania, *Report*, at 24, 78.
3. The Supreme Court of Pennsylvania, *Report*, at 24.
4. 20 Pa.C.S.A. §5512.1(A) (1992); American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*, at 602-03 (5th ed. 2013).
5. D.E. Schiff, C. Kline, J. Auger, J. Willert, W. D. Roberts, A. Reineke, *Effects of a Unique Hematology-Oncology Pediatric Palliative Care Program on Medical Decision-making and Communication Between Health Care Providers and Families*, 29 JOURNAL OF CLINICAL ONCOLOGY, (2016), PMID: 28020933; *In re Fiori*, 543 Pa. 592, 606-07 (1996); *In re D.L.H.*, 606 Pa. 550, 563-64 (2010); *In re Estate & Pers. of Borders*, 68 A.3d 946, 957-58 (Pa. Super. Ct. 2013).
6. 20 Pa.C.S.A. §5521(A) (2018); 20 Pa.C.S.A. §5456 (5)(ii)(A)(2017); 20 Pa.C.S.A. §5462 (c)(1)(2007); *Standards of Practice*, 2013 National Guardianship Association §15(l) at 16.
7. 20 Pa.C.S.A. §5521 (d)(iii) (2018).
8. Erin S. DeMartino Et al., *Who Decides When a Patient Can't? Statutes on Alternate Decision Makers*, N ENGL J MED. 376(15): 1478–1482, at 4 (April 2017).
9. Schiff, *Effects on Medical Decision-making and Communication Between Health Care Providers and Families*, JOURNAL OF CLINICAL ONCOLOGY 29 (2016).