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CONTENTS

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ETHICAL ISSUES IN ADVOCACY BY NONPROFIT ORGANIZATIONS: THE CASE OF LEGAL CONSULTATION AND REPRESENTATION OF OLDER CLIENTS IN ISRAEL

Meytal Segal-Reich, Israel (Issi) Doron, and Sagit Mor*

I. INTRODUCTION

Nonprofit organizations (NPOs; also known sometimes as NGOs or non-governmental organizations) that provide legal consultation and representation for older persons are important in making legal services accessible to the older population. These NPOs specialize in elder issues, with an additional range of activity that includes education and information dissemination, aimed at creating social change. The NPO representation system differs from that of the private sector for both the client and the lawyer because the older population as a group (and not only the individual client) is part of the process (and the goals) even when not physically present. This understanding has engendered the need to examine how lawyers working in NPOs for the promotion of older persons'

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[*] Dr. Meytal Segal-Reich, LLB (Hebrew University, Israel), LLM (Haifa University, Israel), PHD (Haifa University, Israel), is head of Legal Representation Department for Older Persons and Legal Competence affairs in the Legal Aid Department of the Ministry of Justice, Israel. Dr. Segal-Reich is the Academic Director of the Older person's Right's Clinic at the Bar-Ilan University, and teaches Elder Law in the Law Faculty in Bar Ilan University.
Dr. Sagit Mor, LLB (Tel Aviv University, Israel), LLM (NYU School of Law), JSD (NYU School of Law), is an Assistant Professor at the Faculty of Law, University of Haifa, Israel. Dr. Mor is the Academic Director of the Law and Health LL.M. Program at the Haifa Faculty of Law, and the founder of the Collaborative Research Network of Disability Legal Studies at the Law and Society Association.
Professor Israel (Issi) Doron, LLB (Hebrew University, Jerusalem), LLM (Washington College of Law, Washington, DC), PhD (Osgoode Hall Law School, Toronto, Canada), is an Associate Professor at the Department of Gerontology, University of Haifa, Haifa, Israel. Prof. Doron is the Past President of the Israeli Gerontological Society, and the current Chair of the Center for Research and Study of Aging at Haifa University.

rights cope with the unique ethical issues involved with representation.

The aim of this Article is to attempt to answer the following research questions: What are the characteristic ethical dilemmas involved when representing older persons through NPOs? To what degree is there an awareness of ethical conflicts, and what is the scope of the response provided through the rules of professional liability? Clarification of these issues will allow investigation of the need to create a unifying system of rules, as well as a code of ethics, for guidance regarding appropriate professional conduct. While these questions are examined within the unique context of the Israeli legal system and its socio-cultural context, we believe the issues and challenges affect many countries and cultures.

From a methodological perspective, in light of the nature of the topic (ethical dilemmas) and the small number of NPOs that provide legal aid to older persons in Israel, the Authors chose a qualitative methodology for this study. This means that in-depth interviews were conducted with key figures in Israeli NPOs that provide representation and consultation for older persons and their family members. During the interviews, the Authors examined dilemmas that arise when representing older persons and ways of coping with them. The Authors also identified the patterns of assistance and their scope, as well as the limits of the representation. The interviews were conducted with legal advisors and managers of the three leading NPOs for representation of older persons in Israel: "Yad Riva (Riva's hand)—Legal Aid for the Elderly," "The Association of Law in the Service of the Elderly," and "Say Yes! to Seniors" ("Ken LaZaken").

The overall structure of this Article will be as follows: Part I provides a theoretical review of consultation and representation for social groups via NPOs and the common dilemmas that arise. Part I also presents the different aspects related to identification of "older persons" as a social group. Part II presents the Authors' research methodology and findings on a range of issues concerning representation of older persons, which can project onto the decision-making systems of lawyers in the NPOs. Part III presents the Authors' conceptualization of central ethical dilemmas that emerged from the research and discusses the findings regarding how NPO lawyers cope with these dilemmas. Part III presents additional aspects of group representation, which shed light on the lawyer's decision-making system.

II. ETHICAL DILEMMAS IN LEGAL REPRESENTATION OF "GROUPS"

A. Group Representation: Basic Models

Scholars have written widely on the right to legal representation, which has been recognized as a legislative right in the broad context of the law. Even though no legislative right to group representation exists, group representation can nonetheless be viewed as built-in to the laws of procedure.[1] These laws define who is allowed to represent the group and in what manner, e.g., in everything concerning the lodging of a representative claim or concerning affiliation as an amicus curiae.[2]

In group representation, a distinction can be made between individual representation for a case with a group interest, and group representation via organizations or NPOs that specialize in human rights or the rights of a specific group. In NPOs that have the goal of policy promotion or change, individual cases are always represented through the vision of the group issue.[3] Group

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[1] William B. Rubenstein, *Divided We Litigate: Addressing Disputes Among Group Members and Lawyers in Civil Rights Campaigns*, 106 YALE L.J. 1623, 1624 (1997).

[2] *Id.*

[3] *Id.* at 1625.

representation poses a challenge to the standard advocacy pattern, which is based on the individualistic model of focusing on the narrow interest of the client.[4]

To examine the dilemmas that arise in group representation, we must first examine the various group representation models, for which several possible typologies exist. The first accepted typology in this context is a distinction between two types of legal representations: procedural representation, which aims to make the legal system accessible to the target group[5] while overcoming inherent obstructions—on the one hand—and critical or material representation, which aims to challenge the social and governmental order and its expression in the law—on the other hand.[6] The procedural model is characterized by creating change through individual cases and a collection of individual representations, whereas the critical model strives to find collective solutions through well-selected cases.[7] Thus, for example, representation of people lacking in means through a procedural model (equal access) has the stated goal of procedural justice and accessibility to the legal system.[8] However, in the critical model of law reform, the stated goal is to fight against poverty and social exclusion, aspiring to eradicate the phenomenon, or at least to reduce its dimensions.[9] In other words, the type of representation model determines the character and breadth of the goal.

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[4] Abraham Chayes, *The Role of the Judge in Public Law Litigation*, 89 HARV. L. REV. 1281, 1310 (1976); *see also* Linda S. Mullenix, *Resolving Aggregate Mass Tort Litigation: The New Private Law Dispute Resolution Paradigm*, 33 VAL. U. L. REV. 413, 414 (1999).

[5] Marshal Breger, *Disqualifications for Conflicts of Interest and the Legal Aid Attorney*, 62 B.U. L. REV. 1115, 1137–38 (1982). Procedural representation aligns with the "Access Rights Position" in Breger's analysis or the "Individualist Model" in Rubenstein's analysis. *Id.* at 1138; Rubenstein, *supra* note 1, at 1623.

[6] Breger, *supra* note 5, at 1137–38. Critical or material representation aligns with the "Social Utility Approach" in Breger's analysis or the "Democratic Model" in Rubenstein's analysis. *Id.* at 1137; Rubenstein, *supra* note 1, at 1654.

[7] Breger, *supra* note 5, at 1137–38.

[8] *Id.*

[9] *Id*; *see also* Marie A. Failinger et al., *Litigating Against Poverty: Legal Services and Group Representation*, 45 OHIO ST. L.J. 1, 6 (1984).

The critical model, by its very nature, commonly seeks "appropriate" cases, using structured screening strategies to achieve maximum group impact for the stated goals.[10] This is inherently a natural complexity of the model. This potentially creates conflict because of the relatively small emphasis placed on the individual client's problem. On the other hand, some claim that the procedural model, which sets to address the barriers to accessibility to legal systems, places too much emphasis on the individual client's issues.[11] Therefore, the group receives relatively little genuine attention and no suitable strategy is developed to advance the group aims.[12] This raises a dilemma related to the degree of obligation to the target group.[13]

In general, it is argued that within the procedural model, advocacy maintains the client within the existing status quo of social power relations; while in the critical model, the critical lawyer is required to strive to challenge existing institutional and social systems in which the specific legal issue exists.[14] Nevertheless, looking more closely into the procedural model itself, one can actually recognize two different sub-types. The first type of the procedural model is procedural representation for the sake of individual representation, with the goal of making the legal system accessible to individuals in the relevant group.[15] The second type, however, is individual representation directed toward social change through the large number of cases represented.[16] A perception of the

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[10] Thomas M. Hilbink, *You Know the Type . . . : Categories of Cause Lawyering*, 29 LAW & SOC. INQUIRY 657, 681 (2004).

[11] Failinger et al., *supra* note 9, at 7.

[12] *Id.*

[13] *See generally* Hilbink, *supra* note 10, at 668.

[14] Lisa Hajjar, *From the Fight for Legal Rights to the Promotion of Human Rights: Israeli and Palestinian Cause Lawyers in the Trenches of Globalization*, *in* CAUSE LAWYERING AND THE STATE IN A GLOBAL ERA 68, 74 (Austin Sarat & Stuart Scheingold eds., 2001).

[15] *Id.* at 81.

[16] *Id.* at 74, 81.

broad value of individual representation might dictate the mode of action, including its degree of conventionalism.[17] Thus, the representation model not only dictates the type and breadth of the goal, but also the action strategy, and furthermore, the selection and screening of cases.

In all the different representation models presented above, the client usually sets the narrow legal goal according to the individual legal issue. However, the NPO sets the wider goal (in either the procedural or the critical model). Usually, after screening, the narrow goal is "fitted" to the wider goal. The legal strategy can be determined or merely approved either by the client or by the NPO lawyers after thinking together with the client or among themselves, or based on the representing lawyer's experience and professional expertise.

Beyond the "procedural" versus "critical" models described above, there are other typologies of group representation. For example, Hilbink presented a different typology, proposing a distinction regarding the representation model in advocacy for social change called "cause lawyering."[18] The basis for his model is the belief in and promotion of a social goal through legal representation.[19] The difference lies in the means of realizing the goal.[20] Hilbink describes three representation models, with different approaches reflecting and applying each model differently, infusing each one with unique theoretical content and social agendas.[21]

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[17] ISAIAH BERLIN, FOUR ESSAYS ON LIBERTY 127 (1969).

[18] *See* Hilbink, *supra* note 10, at 659.

[19] *Id.*

[20] *Id.*

[21] *Id.* at 665–90; *see also generally* LAURA KALMAN, THE STRANGE CAREER OF LEGAL LIBERALISM 2 (1996) (defining legal liberalism as the potential of courts to bring about social reforms that affect large groups of people); TALCOTT PARSONS, *A Sociologist Looks at the Legal Profession, in* ESSAYS IN SOCIOLOGICAL THEORY 370, 371 (1954).

The first model is yet again a procedural advocacy model, characterized by belief in the legal system as just and fair.[22] Identification is with the broad group goal rather than with the specific case.[23] However, neutrality toward the "system" is maintained and no attempt is made to challenge the legal method or the social structure of the society as such.[24] The second model is an elite-vanguard form of lawyering, in which the lawyers see their goal in the actual outcome rather than the success of the specific procedure.[25] The law is considered a tool for broader social change, where the goal is to actually make a change in the social status of specific groups.[26] The lawyers actively and more carefully choose the specific clients with suitable backgrounds whose individual cases can be used as tools for the establishment of more broad and general legal principles.[27] The third group representation model, which is more a kind of grassroots lawyering, perceives the law as a political instrument of oppression, the legal system as unjust and unfair, and hence, already casts a doubt regarding the effectiveness of the law for promoting social change.[28] According to this model, the law does not provide rational tools to achieve an empirical truth and therefore the logic and analysis of the law have little importance.[29] The goal of this approach is to change society's attitude to certain issues as well as change the structural hierarchy, not only from top-down, starting with the courts (as in the second

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[22] Hilbink, *supra* note 10, at 665.

[23] *Id.* at 665–73.

[24] *Id*; *see also* Michael W. McCann & Helena Silverstein, *Rethinking Law's "Allurements": A Relational Analysis of Social Movement Lawyers in the United States, in* CAUSE LAWYERING: POLITICAL COMMITMENTS AND PROFESSIONAL RESPONSIBILITIES 261, 284–86 (Austin Sarat & Stuart Scheingold eds., 1998).

[25] Hilbink, *supra* note 10, at 673.

[26] *Id.* at 673–81.

[27] *Id*; *see also* McCann & Silverstein, *supra* note 24, at 284–86.

[28] Hilbink, *supra* note 10, at 681–90.

[29] *Id*; *see also* McCann & Silverstein, *supra* note 24, at 284–86.

model), but also to bottom-up, starting with individuals and groups.[30]

The different representation typologies and models can naturally have an impact on the ethical and professional decision-making systems of NPO lawyers and on the type of dilemmas facing the lawyers who use them for representation and consultation. Nevertheless, in general, at least in Israel, no special laws govern lawyers' professional conduct within the NPO system for representation of older clients, other than the general rules of legal practice. In other words, despite the realization that different approaches and models of representation may exist, no specific guidelines are available for lawyers as to how to locate and characterize a group as part of a legal representation by NPO lawyers; or how to ensure that the group interest is indeed represented appropriately while representing a specific client. Neither do the existing rules of ethics address prevalent circumstances or common ethical dilemmas related to the actual group representation via NPOs. A presumed uniformity exists regarding the rules pertaining to lawyers, which are apparently supposed to be suitable for all lawyers in any representation model and in any system.[31] This is true in Israel for all cases of group representation. However, the question is to what extent are there unique issues regarding the representation of older persons—as a special social group?

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[30] Hilbink, *supra* note 10, at 681–90; *see also* McCann & Silverstein, *supra* note 24, at 284–86.

[31] *See* John Basten, *Control and the Lawyer-Client Relationship*, 6 J. LEGAL PROF. 7, 16 (1981).

B. Older Persons as a Group

1. Identifying the Older Persons Group

Group identification stands at the basis of different sociological theories, some concordant and others contradicting.[32] According to some social models, the social system is perceived as dictating people's places and roles, as determining their places in the environment, identifying them with a group, and thus shaping their character.[33] According to some socio-cultural approaches, as a result of interactions in society, the culture dictates signs and images that determine attitudes toward people and their common identification through characteristics found dominant by the culture.[34] The relevant question for the purposes of this study is to what extent older persons have been labeled by the social system and cultural signs as having unifying characteristics, which attach them to a group.

Defining older persons as a unique and separate social group poses a range of theoretical difficulties, despite aspects ordinarily accepted as unifying among its members. Nevertheless, anthropological research has tried to identify and examine the characteristics of the "elderly" as a group. No less than twenty-one characteristics were found within this anthropological approach, including: the fact that older persons are usually a minority in the population; the number of women elders is greater than the number of men; every society has a classification of older persons which dictates rules of behavior toward them; in every society, older persons' activity is reduced; behavioral norms exist between older

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[32] *See, e.g.*, Jan E. Stets & Peter J. Burke, *Identity Theory & Social Identity Theory*, 63 SOC. PSYCHOL. Q. 224 (2000).

[33] Alan Dawe, *The Two Sociologies*, 21 BRIT. J. SOC'Y 207, 210–11 (1970).

[34] *Id.*

persons and their offspring; every society aspires to achieve longevity, etc.[35] Nevertheless, after identifying the characteristics that are associated with older persons as a distinct group, there was still no doubt that, in each specific society, the "older" group had different cultural traits.[36] Moreover, the anthropological theories asserted that the dynamics of modern society dictate a cultural pluralism that prohibits one-dimensional observation of the group of older persons.[37]

Even when we move away from the anthropological approach, it seems quite clear that to most people, old age is relevant to a multitude of dimensions: biological, social, psychological, chronological, and more. However, each of these dimensions is experienced differently on the individual level. Therefore, group characterization that attributes shared characteristics, whose only source revolves around the chronological age of the subjects, poses a conceptual difficulty. A characteristic that is solely age-related only signifies a group that is heterogeneous in the extreme. It includes women and men of different nationalities, people of different socioeconomic statuses, people whose functioning differs on a range of dimensions, people with and without disabilities, with different levels of education, different social involvement, different life experiences, and different cultural backgrounds. Even composing a group of elders, including anyone who is "old," according to parameters of chronological age, is largely artificial, unfounded, and not conducive to intuitive definition.[38]

The anthropology of age has changed in this context. It no longer strives for objective identification of universal characteristics of older persons but adopts a subjective perspective, identifying

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[35] D.O. COWGILL ET AL., AGING AND MODERNIZATION 3–5 (1972).

[36] *Id.*

[37] *Id.*

[38] Ronald Dworkin, *Comment on Narveson: In Defense of Equality*, *in* JUSTICE IN POLITICAL PHILOSOPHY 3 (Will Kymlicka ed., 1992).

people according to their worldviews and beliefs.[39] Even an attempt to define them as a community based on the importance of multiculturalism poses many difficulties.[40] Older persons are not a minority whose culture needs protection from assimilation and disappearance, but they embody multiculturalism in themselves.[41]

Nevertheless, despite the complexity of the definition, older persons have been constructed as a group through regulation and through deeply-rooted and widespread perceptions of them in the society.[42] This has been formed in the context of an important and relevant social phenomenon known as "ageism." While it is beyond the scope of this Article to fully explore and discuss this concept, it is clear that the way society constructs "old age" and "the elderly" results in the need to realize that older people are a distinct social group, like other socially constructed groups, e.g. "women," "persons with disabilities," or "Afro-Americans."[43]

2. *Older Persons and the Law*

Older persons and the law have a bidirectional relationship. The law constructs older persons as a group through legal regularization of their place in society, e.g., regarding their age of retirement.[44] In the legal arena, they are characterized as a population or according to issues relevant to them as a whole.[45] It

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[39] LIFE'S CAREER AGING: CULTURAL VARIATIONS OF GROWING OLD 24 (Barbara G. Myerhoff & Andrei Simic eds., 1978).

[40] Ayelet Shachar, *The Paradox of Multicultural Vulnerability: Individual Rights, Identity Groups and the State*, *in* MULTICULTURAL QUESTIONS 87, 87–88 (Christian Jopke & Steven Lukes eds., 1999).

[41] *See generally id.* at 87–111.

[42] *See generally* PATCHEN MARKELL, BOUND BY RECOGNITION 152–76 (2003).

[43] *See generally* Glenda Laws, *Understanding Ageism: Lessons from Feminism and Postmodernism*, 35 THE GERONTOLOGIST 112-18 (1995).

[44] Lawrence A. Frolik, *The Developing Field of Elder Law: A Historical Prospective*, 1 ELDER L.J. 1, 2 (1993).

[45] *Id.*

can be claimed that older persons have interests or legal issues with different degrees of relevance, which characterize their place in the legal world.[46] An attempt can be made to examine what will be considered "legal issues of older persons" to a greater or a lesser extent—starting with general legal issues that do not specifically characterize older persons, but to which they can be required to adhere. There are more prevalent legal issues with an increase in age, for reasons that are not directly age-related, but are related to biological or physiological aspects, or even accompanying social and financial aspects, e.g., issues involving risk of losing financial or physical independence, and dealing with and maintaining social rights.[47] This is in addition to legal issues involving implications of possible cognitive deterioration, including the possibility of appointing a guardian or a supporter for decision-making. Additional examples of legal issues that become more prevalent with advancement in age are inheritance issues, long-term care insurance, and various consumer issues.[48] Furthermore, some legal areas are identified with the end of life, such as preventive planning for medical issues or finances, including drawing up a will, appointing powers of attorney for bank accounts, etc.[49] In addition to these, the issue of ageist discrimination from a variety of aspects exists, e.g., regarding work.[50] Even though not all older persons experience this in the same way, it is not too far-fetched to assume that they are all in favor of its elimination.

Nevertheless, even apparently unifying issues do not have identical implications among older persons in general, and there is no absolute unification in related goals and aspirations.[51] For example, it cannot be assumed that the fight against a compulsory

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[46] *Id.*
[47] *Id.*
[48] Frolik, *supra* note 44, at 2; *see generally* Edgar S. Cahn, *Reinventing Poverty Law*, 103 YALE L.J. 2133, 2135 (1994).
[49] Frolik, *supra* note 44, at 2.
[50] *Id.*
[51] *Id.* at 2–3.

retirement age, in which age-based discrimination is manifested, is common to all, but there will be those who will find reasons to justify a fixed retirement age.[52] Unification is not obligatory for group identification in the "legal world," as in the case of poverty law, which, despite heterogeneity and a wide range of legal issues and approaches, identifies "poor people" as a "group" in law.[53] Regarding this group, unifying insights are determined, among other things, regarding the question of accessibility to the legal system, as a parameter for identifying the group.[54] The group of older persons is constructed within a legal content category in itself, known as Elder Law, a discipline that includes the same issues, with variable degrees of relevance to one older person or another.[55]

3. *Identifying Specific Contexts in the Older Persons Group for Their Group Representation*

The more the older persons group is limited to a narrow legal context or to a concrete issue, the less significant the age parameter will be by virtue of the unifying issue.[56] Moreover, even if we take a group of older persons with unifying legal issues, NPOs differ in their methods of screening clients.[57] If applicants undergo a means test, for example, then the aid will be provided only to those who meet the financial criterion.[58] In such a case, the representation will

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[52] *See, e.g.,* Ann Numhauser-Henning, *The EU Ban on Age-Discrimination and Older Workers: Potentials and Pitfalls*, 29 INT'L J. COMP. LAB. L. & INDUS. REL. 391, 393 (2013).

[53] *See generally* Juliet M. Brodie, *Post-Welfare Lawyering: Clinical Legal Education and a New Poverty Law Agenda*, 20 WASH. U. J.L. & POL'Y 201, 228–30 (2006).

[54] Meltzer v. C. Buck LeCraw & Co., 402 U.S. 954, 955–61 (1971).

[55] Frolik, *supra* note 44, at 1–3.

[56] Frolik, *supra* note 44; *see also* JEROLD S. AUERBACH, UNEQUAL JUSTICE: LAWYERS AND SOCIAL CHANGE IN MODERN AMERICA 56 (1976).

[57] *See* Frolik, *supra* note 44, at 9 (where law schools use screening methods for pro bono work by students).

[58] *See id.*

be for "poor older persons," according to the determined criteria, a specific group within the overall older persons group.[59]

It is interesting to note, however, that old age is a uniquely unified group, despite its conspicuous internal heterogeneity. Its uniqueness lies in the fact that everyone may be included in it. When legally representing older persons, one is actually representing a broad interest of the entire population, including the older persons of today and those potential of the future.[60] This notwithstanding, a broad definition of the older persons group as including the entire population, even if based on facts, actually creates a paradox, since it apparently negates the possibility of identifying characteristics of a group or of an immediate, unifying interest.

It can be concluded that even though different social theories conceptualize a group of older persons, the definition still involves a difficulty that requires coping with the claim that age is not a parameter through which a group of people can be categorized, in addition to the group's tremendous heterogeneity and the theoretical possibility of incorporating the entire population.[61] Not only do NPOs lack complete knowledge about the individual elders to whom a specific legal issue is directly relevant, and about their attitude to the issue, they also do not, in many cases, have a concrete method of evaluating the scope of the relevant group as part of the older persons group. Nevertheless, concerning the legal world, it is accepted that prevalent characteristics of "older persons issues," to a greater or a lesser extent, can serve as parameters for strengthening

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[59] *See id.*

[60] *See generally* CHARLES TAYLOR, *The Politics of Recognition*, *in* MULTICULTURALISM 25 (Amy Gutmann ed., 1994); *see also* Jeff Greenberg, Jeff Schimel & Andy Martens, *Ageism: Denying the Face of the Future*, *in* AGEISM: STEREOTYPING AND PREJUDICE AGAINST OLDER PERSONS 27, 28 (Todd D. Nelson ed., 2002) (discussing the uniqueness of "the elderly" as a group and "ageism" as a social phenomenon).

[61] *See* TAYLOR, *supra* note 60, at 41.

the definition of older persons as a group beyond the technical issue of chronological age.[62]

III. PRESENTATION OF THE RESEARCH

The aim of the study was to examine and conceptualize ethical dilemmas facing lawyers in NPOs for consultation and representation of older persons.[63] In general, older persons and their families have several possible channels through which to receive legal information, consulting, and representation services in all of the three accepted sectors: in the government sector (the range of legal consulting services provided by the state and its institutions); in the private sector (private lawyers in the free market); and in the third sector (NPOs for legal advocacy and empowerment).[64] The third sector in Israel has a large specialization in the field of legal consulting in old age, including the NPOs whose goals are to change accepted policy and advance older person's issues. The NPOs usually provide information and guidance services, as well as assistance with initial correspondence, whereas legal representation is provided, on the whole, for mostly strategic litigation and precedential issues, which have implications for a significant portion of the older person's population.

The sample chosen for the study comprised the three main NPOs in Israel for representation and consulting for older persons:

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[62] *See* Frolik, *supra* note 44, at 2–3. The dilemma around the justification of recognizing "older persons" as a distinct "group" can also be seen in the recent international debates around the justification of a new, distinct human rights convention for older persons. *See* Israel Doron & Itai Apter, *The Debate Around the Need for an International Convention on the Rights of Older Persons*, 50 GERONTOLOGIST 586, 586 (2010).

[63] The research presented in this article is on file with the Authors and is available upon request at idoron@univ.haifa.ac.il.

[64] *See generally* Frolik, *supra* note 44, at 17.

(1) Yad Riva (Riva's Hand), legal consulting for elders,[65] (2) the Association of Law in the Service of the Elderly,[66] and (3) Ken LeZaken (Say Yes! To the Elderly), the civil forum for the well-being of elders.[67] In this research, the authors adopted the qualitative method, i.e., a study that attempted to elicit the content and meanings as expressed through the personal experiences of the lawyers involved. Regarding procedure, the study included in-depth, open-ended interviews based on a pre-prepared interview guide and analysis of the findings that emerged. For the purpose of the study, we located NPOs for consulting and representation of elders in Israel through searching online databases and official websites, such as of the Ministry for Social Equality,[68] the Reut-Eshel website of Joint-Israel,[69] which includes concrete information about the NPO's legal services, the SHEKEL website—organizations that assist people in old age,[70] etc. The search revealed that several NPOs that deal with older persons issues are in operation in Israel. Each NPO has different operation patterns in the type of services that it provides, as well as in specialization. Most of them are local community NPOs.

IV. *FINDINGS*[71]

From the data collected in the interviews with the NPO representatives, central parameters were summarized and condensed into the following table, allowing a comparison among the different NPOs regarding the relevant issues.

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[65] YAD RIVA LEGAL AID, http://www.yadriva.org/ (last visited July 8, 2019).

[66] ASSOCIATION OF LAW IN THE SERVICE OF THE ELDERLY, http://www.elderlaw.org.il/ (last visited July 8, 2019).

[67] KEN LAZAKEN, http://www.kenlazaken.org.il/ (last visited July 8, 2019).

[68] MINISTRY FOR SOCIAL EQUALITY, https://www.gov.il/en/Departments/ministry_for_social_equality (last visited July 8, 2019).

[69] REUTH FAMILY CARE, http://www.reutheshel.org.il/index.aspx?id=3243&itemID=3490 (last visited July 8, 2019) (select English to view).

[70] SHEKEL: COMMUNITY SERVICES FOR PEOPLE WITH SPECIAL NEEDS, http://www.shekel.org.il/ (last visited July 11, 2019).

[71] The following section includes information gathered from the Authors' own research.

Table 1: Main Characteristics of the Three NPOs

	Ken LeZaken	**Association of Law in the Service of the Elderly**	**Yad Riva**
Year of establishment	2004	2002	1984
Financial criterion for providing services/ consulting	None	None	None (in cases of abuse/neglect), but services such as making a will are not provided to people of means.
Age criterion for providing services/ consulting	None Services provided also to elders' family members.	None Services provided also to elders' family members.	Services provided also to elders' family members, as long as this pertains to a man over 60 or to a woman over 65.
Material criterion for providing services	Yes Elder issues	Yes Elder issues	The service is designated according to age criterion on every issue.
Number of workers	3 part-time, 1 National Service volunteer.	1 full-time, 1 part-time.	3 full-time, 3 part-time.
Number of salaried lawyers	1 part-time.	1 full-time.	2 full-time, 2 part-time.
Volunteer lawyers	Professional volunteer with a legal background.	Yes—on the management committee and the legal committee.	Approximately 85.

	Ken LeZaken	**Association of Law in the Service of the Elderly**	**Yad Riva**
Expected expansion in pool of lawyers?	No—the NPO does not provide private legal services.	No—due to lack of resources.	Would be welcome—logistic difficulties (mentoring, monitoring, managing applications).
Is most of the service in consulting and imparting information or in providing legal services?	Consulting and imparting information; Solving individual problems.	Consulting and imparting information.	Legal consulting and initial correspondence.
When is there an application to the law?	In precedential cases.	In precedential cases.	Protection of elder's well-being, cases of exploitation, abuse, and neglect.
Cooperation with other organizations	Yes—mainly with coalitions.	Yes—mainly with elders and pensioners organizations.	Yes—mainly with the Ministry of Social Affairs and Social Services and the Ministry of Health.
Number of applications to the NPO in 2011	Approximately 1,000	Approximately 1,000	Approximately 6,500
Geographical distribution	Telephone service only—services the whole country.	Office in Haifa – serves the whole country.	22 branches—provides accessibility to services for outlying areas.
Payment by applicants?	No	No	No

	Ken LeZaken	**Association of Law in the Service of the Elderly**	**Yad Riva**
NPO funding: public/private/ both	Private funding	Private funding—endowment fund.	Private funding—local municipalities and government ministries.
Works with "clients" or "applicants?"	Applicant	Applicant	Applicant
Frontal meetings	In general, no	In general, no	According to need
Number of cases in 2011 in which the NPO initiated legal action	None	2	Dozens (estimate)
Number of cases in 2011 in which the NPO became an Amicus Curiae	None	3	None
Main goal	Social change	Social change	Accessibility of legal services to the elder population, bottom-up change.
Ethical code for NPO lawyers	None	None	None
Older persons in the NPO	Yes, volunteers on the council.	Yes, volunteers on the management committee.	Yes, approximately 40% of the volunteer lawyers are over 60, and 8 on the management committee.

	Ken LeZaken	**Association of Law in the Service of the Elderly**	**Yad Riva**
Older persons among NPO workers	None	None	None

From the aforementioned data, it appears that of the three leading NPOs for older persons' issues in Israel, only Yad Riva works according to a procedural legal model. The NPO defined its goal as making legal services accessible to the older population and providing individual legal services and creating change through the many individual cases. This is a bottom-up method, not based on a grassroots model, but as part of a procedural model. The study shows that the Association of Law in the Service of the Elderly works according to a critical representation model and for purposes of the representation, screens cases according to their degree of potential influence on the elder group and according to the degree of precedential potential of the case and the applicant. Nevertheless, telephone consultation is also provided to all applicants, regardless of its relevant importance to the whole group. Ken LeZaken, as revealed by the study, provides consulting to anyone who asks and even helps with initial correspondence. Its main activity regarding older persons' issues is the creation of a lobby and intensive work in Knesset coalitions to advance social change. It is interesting that this is the only NPO whose legal advisor defined it as a human rights organization and its actual goal does not concern elder issues only.

According to Hilbink's model, Yad Riva can be identified with the first, procedural model and the Association of Law in the Service of the Elderly with the second, critical model. If each model has a core, space, and boundaries, then Ken LeZaken can be located at the boundary of the third, grassroots model. On the one hand, it does not undermine the legal system or take "revolutionary" steps in an illegal sense, but on the other hand, it focuses on the public level, mainly through lobby in the Knesset and through cooperating with other social organizations in the field of aging . At the same time, the NPO organizes demonstrations and integrates community work actually in the field, from the lowest level. This is in the attempt to effect grassroots change and not necessarily by creating a legal precedent through representation of a material case. The fit to the models is not complete, which is a reasonable finding, considering that even Hilbink noted that definitions cannot be fitted precisely to actual representation patterns.

The study reveals that the Association of Law in the Service of the Elderly identifies the advantages of NPO representation over private representation by creating inexpensive accessibility to rights. The advantages of representation by Yad Riva are its expertise in the field, as well as its geographical accessibility to elders. The NPO tackles the problem of isolation and the absence of a support system, as well as additional personal and family issues, for the older person's benefit. Of the three NPOs, Yad Riva is the only one that holds frontal and personal meetings with older applicants in its offices and is concerned mainly with providing immediate legal consulting rather than leading change through strategic and precedential cases.

An interesting finding of the study is that the three NPOs reflect three different approaches, not only regarding the representation model, but also in the context of the essence of the professional relationship with the applicant. Yad Riva recognizes the lawyer-client relationship and asks the applicants to sign a power of attorney so that the NPO can take action and send a letter on their behalf, and applicants become “clients” through their signature. The Association of Law in the Service of the Elderly takes an “intermediate” approach; the NPO does not provide legal representation but only telephone or internet (email) based consulting. It does not formally recognize a lawyer-client relationship, but in practice, does take on professional obligations because the consulting is provided through the NPO's legal advisor. Ken LeZaken does not recognize lawyer-client relationships at all. The consulting is provided by the NPO's volunteers, who are not lawyers, and the legal advisor operates generally on broad levels of changing policy and not in providing legal services to applicants.

It is interesting to note that none of the three NPOs have an ethical code for the lawyers in the organization. Decisions on ethical issues are made by the managers or the professional leaders in each NPO in accordance with its own operating strategy. In *Yad Riva,* the NPO's salaried lawyers made the decisions on ethical conflicts. In the other NPOs, the management committee decides after examining and clarifying the issue. There is no orderly decision-making system or guidelines, and the decision depends on considerations and the circumstances of each individual case, on a case-to-case basis. It is also interesting to note that the interviewees did not raise the dilemma of the "identity" of client itself (i.e. the individual or the group). It seemed, in essence, not to be perceived as an ethical issue. In two of the NPOs, the central ethical conflict was identified with different aspects of providing services to people experiencing cognitive deterioration. In addition, it emerged from the study that the three NPOs operate in cooperation with relevant professional authorities in the field to advance their goals.

Following this review of the background and characteristics of each of the three NPOs, the Article will now present the NPOs' degree of awareness and ways of coping with central ethical dilemmas, as they emerged from the study findings. A brief conceptualization of the central dilemmas and a presentation of the findings will be followed by a theoretical discussion of these core dilemmas, which pose a professional challenge to the lawyer.

A. The Screening Dilemma

The screening dilemma involves, in theory, the dilemma around selecting the individual cases for which legal aid and representation will be provided. Due to limited resources as well as in its legal mandate, it is clear that NPOs cannot provide representation or even consultation to all applicants. Therefore, a screening mechanism must be put in place.[72] The screening can be procedural in nature, for example, revolving around the question of financial eligibility (means testing), and the area of professional services (the technical aspect—does the NPO have the capacity to provide the needed aid), or around the question of the legal issue (to what extent is it an "elder law" issue).[73] The screening can also be based on a more material nature, and may involve issues concerning the tactical aspect of selecting the case that is "right" or "fitting" for a petition to the court.[74] In the latter case, even a legitimate older applicant can potentially be rejected due to the fact that the case does not involve "significant" or "precedential" elements.[75] In any case, the screening process should be scrutinized more than once[76] as it may harm older people, who did not receive representation, for the sake of what is viewed as the broader interests of the group.[77]

The study showed that in practice, the three NPOs do not perform initial procedural screening in the technical sense, but rely more on legal-content screening, to ascertain that the cases are related to elder issues (and if they are not viewed as "elder law issues"—e.g. disputes between neighbors—then they are screened

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[72] Hilbink, *supra* note 10, at 681.
[73] Frolik, *supra* note 44, at 2–6, 8–10
[74] Hilbink, *supra* note 10, at 681.
[75] *See id.*
[76] Marshal Breger, *Legal Aid for the Poor: A Conceptual Analysis*, 60 N.C. L. REV. 282, 286–97 (1982).
[77] Hilbink, *supra* note 10, at 681; *see also* James B. Pearson, *To Protect the Rights of the Poor: The Legal Services Corporation Act of 1971*, 19 U. KAN. L. REV. 641, 642 (1971).

out). In the Association of Law in the Service of the Elderly and Ken LeZaken, legal consulting is provided to anyone applying to the NPO regarding elder law issues without any other screening. However, providing legal aid which goes beyond general consultation, e.g. petitioning to the court and representation, is given only in few and rare cases which are viewed as widely influential and potentially precedential issues, according to a very thoughtful material screening.

Yad Riva, on the other hand, provides legal consulting services to all applicants as long as the applicant is an older person (regardless of the fact that the legal issue itself is an "elder law" issue) and has no financial criteria. Moreover, it provides actual legal representation, without any means testing, in all cases that involve exploitation, neglect, and abuse of older persons. However, it does have financial criteria for the provision of legal services beyond consulting, in special cases, according to discretion regarding the subject matter and the circumstances. This is up to the personal discretion of the lawyer and is not included in any formal criteria or rules

B. The Funding Dilemma

The screening of cases is not the only determining factor regarding the scope and nature of the legal services. The NPO budget plays a central role, which affects the different activity options. These often go beyond legal representation in a specific procedure, such as in the community, in the explanation and dissemination of information, and in utilizing social tools to create change. Budget limitations can determine the scope of the relationship with individual clients and the scope of legal services that will be provided to them. The entire relationship will sometimes amount to just one telephone conversation or one meeting. The lawyer will sometimes act informally on behalf of the individual client, such as by sending a letter or making a phone call to clarify the legal issue or in an attempt to advance an arrangement. Larger resources allow the employment of a larger number of workers, an increase in the scope of legal services provided and publicity that can lead to more applications, and to increased funding, accordingly. Even if the NPO relies on volunteers, funding is essential even for basic running costs such as administrative infrastructure and necessary office equipment for providing services.

The funding dilemma surrounds not only the question of limited resources, but also the relationships with donors or financers. Many NPOs rely on philanthropy, grants, and donations. Many NPOs have to report to their donors on their activities, and provide justifications for their financial decisions. While the actual practices vary significantly, in reality issues such as conflicts of interest or informal expectations can actually limit the operations of the NPOs. For example, if an NPO receives a significant donation from a pharmaceutical corporation, how would that affect its liberty in taking a case of an older client against that corporation or against the pharmaceutical industry in general?

From the interviews in this study, the funding dilemma emerged as the most widely recognized dilemma among the NPOs and to which they devote the most significant attention. An internal discourse in all three NPOs offers a conscious, material response. The study shows that all the NPOs maintain ongoing contact with their financers, even though they are not part of the decision-making process in individual cases. As part of the relationship, the NPOs periodically provide the financers with general financial reports about their activities. This is in addition to extensive ongoing fundraising correspondence to enlist additional donors.

To cope with the funding dilemma, Ken LeZaken, for example, for ideological reasons, is funded only by private, non-governmental bodies that have potentially no conflict of interest with elder rights. Ken LaZaken specifically refuses to accept state budgets from the Ministry for Social Affairs to avoid a potential conflict of interest. The Association of Law in the Service of the Elderly refuses to accept funding from government ministries for fear of losing its independence and refuses funding from individual bodies with which they might have a conflict of interest, such as assisted living facilities or nursing homes. Nevertheless, LSE does not refuse donations from organizations or associations, such as The Nursing Home Association, and others.

Yad Riva is the only one of the three NPOs that is financed also by public funds, including local municipalities and government ministries. Nevertheless, on principle, they do not receive funding from senior citizens' homes, for fear of a conflict of interest. The NPOs explain that despite the difficulty and the frequent need for the NPOs' lawyers to write letters of complaint to local municipalities who also provide them with funding (e.g., regarding unjustified property tax), the NPOs do use their connections with the various incumbent authorities to settle the applicants' issues. Thus, the connection with the financers is channeled toward the good of the subject.

C. The Dilemma of "Who is the Client"

In general, the ethical dilemma of "who is the client" is well known within elder law practice. In light of the common involvement of family members or other third-parties, it can sometimes become "blurred" who is the actual client, and to whom does the lawyer owe the professional duties. However, the findings of this research dealing with NPO lawyers coping with the dilemma of "who is the client"" showed that, in general, the NPOs are unaware of the ethical difficulty regarding the definition and identification of the client. In two of the NPOs, the stance is that lawyer-client and lawyer-applicant relationships do not exist, and therefore the applicant is actually not considered a "client" for the purpose of "lawyer-client" relationships. Only Yad Riva takes the fundamental approach of lawyer-client and lawyer-applicant relationships. The applicants are asked to sign a power of attorney for the NPO and the relationship is a completely professional one. The stance is that "the older person is always the client" regardless of the services he or she receives.

The findings of this study also show that all three NPOs do not consider imparting information to family members or working together with family members as raising an ethical dilemma. Only in cases of a clear and serious conflict of interests between an older person and a family member would alarm bells ring. Only then would the NPO either not be prepared to assist on the request of a family member, or assist only after assessing the well-being of the elder in-and-by him/herself. It is interesting to note that beyond family members, none of the NPOs mentioned or identified as a "client" any other entity, or the group of elders, or any other relevant or involved authority.

D. The Dilemma of Professional Loyalty

The ethical dilemma of loyalty involves a potential conflict of interest due to NPO lawyers' large number of potential professional loyalties: i.e., to the applicant, to the whole social group (i.e., the older persons), or to the NPO itself. The findings of this study show that lawyers in Ken LeZaken are aware of the theoretical possibility of a loyalty conflict between the individual and group interest, even if they have not actually encountered such a case. Their basic approach is to focus on solving the individual problems. However, when an individual issue is perceived to have public impact, the individual is then asked for his or her specific consent to join a more extensive proceeding, such as a petition to the High Court of Justice. The "move" from the more "client" based proceeding to a "group" based proceeding is done only after consultation and agreement with the client. Moreover, when a broad social issue arises, Ken LaZaken tries to take an "open-based" approach in the form of a social campaign that allows the members of the older group the freedom of choice. For example, in the legal struggle around the abolishment of compulsory retirement, the NPO's stance advocated a flexible retirement age, leaving the choice up to the individual, thereby avoiding a conflict between the individual and the group.

The Association of Law in the Service of the Elderly defines its main goal as creating social change, which includes policy change and changing the society's perception of elders, showing clear inclination of loyalty towards the relevant interest group. As mentioned, this NPO does not perceive the applicant for services as a "client" because representation involves only the imparting of information and consulting. Nonetheless, it was found that there is room to uphold ethical obligations, such as confidentiality and fidelity, toward the applicant, since the legal consulting is provided by a lawyer and not by the NPO as such. In the case of a specific conflict of interest between the client and the group, the client's interest takes precedence. Even when the group interest is lost to the wishes of the individual client, the immediate obligation is still to the individual, who is not an instrument for accomplishing a social goal, unless the interests merge and the individual client is completely willing to cooperate.

Yad Riva defines its goal as providing older persons with accessible legal services, implying that their focus is on the individual, and therefore this NPO is consistent with the procedural representation model. In other words, loyalty to clients is not derived from a perception of the group issue, but from the individual issue only. If that is the case, the criterion for decisions regarding the loyalty issue is not derived from the rules but from an internal principle of the NPO.

The study shows, therefore, that within the NPO, there is no real sense of conflict regarding loyalty to clients, which requires ethical coping and decision-making. In all three NPOs, it was found that representation of the client prevails over the group issue and over the wish for a precedent that will lead to change, but not on the basis of guidelines. None of the interviewees identified a conflict resulting from their loyalty to the NPO as an entity, despite the fact that the individual might serve as a means through which the NPO can challenge broad public and legal policy, which might spark a clash of loyalties.[78] Thus, for example, the NPO as an entity has an interest in publicizing and creating a legal precedent. An immediate solution in the form of proposing a compromise, such as in the framework of a legal proceeding with wide-scale potential, contradicts the NPO's aim of reaching a decision that will have implications for the public. The NPOs have an inherent interest in an ongoing proceeding, which will move through all the courts of appeal, to achieve an outcome with precedential value as a result of publicity and support. Therefore, it is interesting that none of the interviewees identified either a conflict on this level, a political impact as the basis of a conflict, or any other loyalty conflict.[79]

E. Identifying the Group Interest

Another critical ethical element in group advocacy is actually identifying what is the group's interest. While in some instances this may be easy and consensual, in other cases it may be very hard to identify, or it may split and divide the group itself. This issue of identifying the older group's interest was also studied through interviews with NPO lawyers to examine how the NPO clarifies what the "interest of older persons" is, in accordance with the NPO's goals. The findings show that not only do the NPOs have

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[78] Hilbink, *supra* note 10, at 684.
[79] *Id.* at 692–93.

no practical way of empirically identifying the elders' group interest, but neither do they act to locate or identify it through action via communication or interaction with the older person's representative groups themselves. The NPOs are not representative of membership organizations that necessarily represent any authentic or broad constituency of older persons. In most cases [80] these are small voluntary organizations based on professionals or local leadership.

In the current study, the interest of the older person's group was commonly determined based on the NPO leaders' ideological platform. This "ideological platform" was continually revisited when coping with new issues as part of the NPO's internal discourse and proceedings. The interest of older persons is identified out of the sense of expertise and experience in the field and out of the understanding that relies on an ongoing relationship with older persons. Therefore, NPOs representing elders in Israel act out of a "model of expertise" and the lawyers represent the group interest, as identified and defined by the NPO. That is to say, they actually represent a hypothetical group interest.

Specifically, the study reveals that Ken LeZaken holds council meetings to form policies and a consensus regarding the different issues. The NPO explicitly states that it promotes its members' ideological perceptions; in other words, no attempt is made to claim that the ideology is of "elders." Furthermore, the NPO is sometimes active in significant social campaigns against prevalent attitudes of other ideological groups who represent elder issues.

The Association of Law in the Service of the Elderly identifies the group interest out of continuous involvement with elder issues by dealing with applications, as well as based on research in the field and classic practice of representation through expertise. The NPO acts to promote the elders' freedom of choice

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pertaining to significant issues and to advance equal participation policy.

Finally, in Yad Riva also, ideology is formed out of the expertise and through ongoing work with older persons. The interest of older persons is manifest in freedom of choice, and hence, older persons can choose, for example, whether or not to be accommodated in a senior citizens' facility.

All three NPOs stressed their ongoing interaction and connections with older persons as part of their basis to identify the group's interest. The study reveals, for example, that Ken LeZaken has an email contact list of members, who periodically receive information and updates, but not on an organized regular basis. In this manner, the NPO remains in contact with the group of older persons, which includes anyone who has applied and requested to join. In the nature of things, the list is presumably not made up exclusively of the group of elders, but can also include people who applied on behalf of family members or out of general interest. In addition, this contact takes the form of transmission of information from the NPO to the group, with no practical possibility of feedback for the purpose of identifying the group interest. Yad Riva retains contact with the elder group, mainly via lectures in day centers, senior citizens' clubs, and old age homes, through disseminating critical information, e.g., on issues of financial exploitation. It is estimated that, thus far, approximately 100,000 people have attended these lectures over the years.

It is an inescapable fact that the relationship with the elder group is one-sided, mainly in disseminating information to the public via lectures, or by the more popular medium of websites. These three NPOs do not act to identify a group interest, but work out of an independent ideology, usually for the sake of maintaining the elders' freedom of choice, based on the assumption that this is the solution that can reflect the group interest in the best possible way. Therefore, lawyers are advocating the interest of a group whom they have not necessarily met with on an individual level and whose interest was identified by the NPO that they represent.

To summarize the key positions of all three NPOs in all key ethical issues, the following table has been produced:

Table 2: Coping with the Five Central Ethical Dilemmas in the NPOs Under Study

	Ken LeZaken	**Association of Law in the Service of the Elderly**	**Yad Riva**
The screening dilemma	**Procedural screening**—elder issues. **Material screening**—representation in precedential cases only, consulting and assistance, without representation for all elder issues.	**Procedural screening**—elder issues. **Material screening**—representation in precedential cases only, consulting and assistance, without representation for all elder issues.	**Procedural screening**—elder issues and financial screening except in cases of exploitation and abuse. **No material screening**
The funding dilemma	**Acknowledges the dilemma** and therefore refuses public funding and funding from authorities with whom they might	**Acknowledges the dilemma** and therefore refuses public funding and funding from old age homes or nursing agencies. Does not refuse	**Acknowledges the dilemma**, coping is according to the issue with a conflict of interest, does not refuse public funding.

	Ken LeZaken	**Association of Law in the Service of the Elderly**	**Yad Riva**
	have a conflict of interest. **Prevention**	funding from associations. **Prevention**	***No*** **prevention**
The "who is the client" dilemma	No "client."	No "client."	The elder is always the client.
The loyalty dilemma	The applicant's issue takes precedence over the group issue. No additional conflicts of loyalty.	The applicant's issue takes precedence over the group issue. No additional conflicts of loyalty.	The aim of the representation is to make services accessible to elders, without a group interest. No conflict of loyalty identified on other levels.
The group interest dilemma	Human rights organization that sees the benefit of the general public. Ideology formed out of the NPO's expertise and through the renown of the representing lawyer.	Preserves the individual's freedom of choice. Ideology formed out of the NPO's expertise and through the reputation of the representing lawyer.	The group interest is making services accessible to elders. Ideology formed out of the NPO's expertise. Represents individual cases not group cases.

V. DISCUSSION

In this section, we will discuss the central dilemmas that were found and presented above. Moreover, we will try to conceptualize them and present their different aspects, characteristics, and ways of coping with them.

A. The Funding Dilemma: The Fear of a Conflict of Interest

Funding issues are critical to the NPOs' functioning. These organizations are not-for-profit according to the law. They are funded both by private and public bodies, which are many times involved in how their money is spent and receive regular reports about the NPOs' activities. A dilemma can arise when, for example, a not-for-profit organization is funded by a certain senior citizens' home network and an elder requests legal representation to file a claim against a senior citizens' home in that network. As such, a situation is created in which the NPO lawyers require the NPO to file a claim against its financers, which constitutes an inherent conflict of interest for the lawyers, whose activity and work are subject to continuation of the funding.

During material case screening, funding might also have an impact when the NPO must choose between two cases: an application for representation against a senior citizens' home that is part of the funding network and an application for representation against a different private authority. In the material screening process, the NPO, or its representatives, must decide which of the cases will receive representation. On this level, therefore, the funding dilemma can manifest a potential conflict of interest between the individual client's issue and the financer. Considering the financer to be a part of the calculation balance in an individual case will always present the lawyer with a dilemma. In addition, the financing body is party, to some extent, to determining the legal strategies and aims, and is a stakeholder in publicizing and advancing its own independent agenda and ideology. Its continued support is subject to its satisfaction with the NPO's activities.

The situation described above might create repeated conflicts and appears to necessitate the setting of guiding principles. At least in the findings of this study, the NPOs were not blind to this potential ethical dilemma. However, none of them had any clear and established guidelines, and in practice each NPO acted differently. Therefore, it could be argued that NPOs who represent older clients should make the effort to establish internal guidelines, regarding the receipt of funds as well as other aspects of their relationships with the financers. Such guidelines could, for example, include a policy of full transparency for the financers and their representatives, providing the financers with a document clarifying the NPO's obligations in the case of a dilemma. It may also include full transparency to the older clients, who will be able to know the identity of the funders of the NPO and their interest in aging and older persons. A more simple approach, which was adopted in part by the Israeli NPOs, is to simply adopt a policy to avoid receiving funds from bodies who may place the NPO in a situation of conflict of interest (e.g., entities which have frequently been sued in the past for elder issues). This, however, may not be easy; many times NPOs have no choice but to rely on public funding—while the issues and policies they promote go against the policies of the public agencies which provide the funding. Many times it is very difficult to raise funding, and those who eventually open their pockets are those who can potentially be the bodies where human rights of older persons are infringed (e.g., nursing homes). Hence, as seen in this study, while there is no one single and perfect solution, NPOs cannot and should not escape dealing with and deciding on this dilemma, while preserving their ethical duty to their clients and to their social goals, and avoiding conflicts of interest.

B. Who Is the Client?

Unlike the dilemma around the potential conflicts of interest regarding funding, the ethical issue regarding the question of "who is the client" was not considered as a real dilemma in the participating NPOs. However, the NPO lawyer's client is not a traditional client. The aims of the legal procedure are not determined only according to the individual's issue, but also in the context of and in light of the legal interest of the whole "older" group. The precedential potential and the implications for social change are also taken into consideration. In reality, representation focused on the broad interest can lead to certain situations where the interests of the individual client may be examined "above his head" from a broad social perspective. The individual case might be submerged into the general issue and even be used as a mere instrument to accomplish the group goals. Among other things, the individual client's involvement and control is reduced in practice, as it is examined and chosen in the shadow of the group issue.[81]

Academic literature in the field has pointed to the fact that representation by an NPO lawyer may differ from the accepted type of representation in individual representation.[82] In many cases, NPO lawyers have reduced control over the individual representation tactics because of the involvement of other members of the NPO in navigating the proceedings. Moreover, the strategies are influenced by broad considerations beyond the individual issue and the lawyer is subordinate to the NPO policies, as well as being committed to its goals and guidelines, and subject to its limitations. Under these circumstances, paying attention only to the individual

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[81] Rubenstein, *supra* note 1, at 1645.

[82] *See, e.g.,* James A. Cohen, *Lawyer Role, Agency Law, and the Characterization "Officer of the Court",* 48 BUFF. L. REV. 349, 349–50 (2000) (applying agency law to analyze the duties that lawyers owe to clients and the role of lawyers as "officers of the court").

client's narrow issue can not only be considered unreasonable,[83] but may cause potential harm to the group's interests.[84]

Group representation can be also an added burden to the individual representation as it may bind individuals to the group against their will. The individual client might not be seeking the representation as part of the social context and the group might prefer to find a more suitable case through which to accomplish the goal. Clients are not necessarily oriented toward a procedural or critical representation pattern. In many cases, they simply wish to receive the best possible representation without any broader interest. Elder clients apply to the NPO because of its expertise and experience in the field and not necessarily because of their political self-identity. In other words, the connection between the individual and the group in representation through NPOs is sometimes artificial and does not necessarily reflect a true bonding of the two. If the uniqueness of the representation through an NPO, as described, is not sufficient, not only is the client not a regular client, but there might be several potential clients, each with their own unique characteristics and the lawyer must decide among them.

But the dilemma around the identity of the client is not limited to the individual older person versus the older person's group. Besides the dilemma between the individual client and the group of older persons, the lawyer is usually an employee of the NPO, and is subject to its dictates, instructions, and authority. It is under the auspices of the NPO that the lawyers provide their professional services by representing the elder clients.[85] Therefore, the lawyer is bound to the NPO regarding professional obligations

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[83] R.A. Phillips & J.D. Margolis, *Toward an Ethics of Organizations*, 9 BUS. ETHICS Q. 619, 627–28 (1999).

[84] Rubenstein, *supra* note 1, at 1652–53.

[85] *See* MODEL R. PROF'L CONDUCT 1.13 (AM. BAR. ASS'N 2016).

and must uphold its legal standards and the nature of the professional relationship. In some sense, the NPO itself is also the lawyer's "client."[86] If this is not enough, reality may become even more complicated when the older person's family member gets involved. As commonly happens in the private sector as well, in meetings with the lawyer, elder clients are often accompanied by family members. These family members many times take active roles and speak on their behalf or on behalf of their older relative. Therefore, the lawyer is now faced with a much more complex "client dilemma" beyond the dilemma of individual representation.

From the picture described above, it seems that potentially there are four different "clients": The older person; his/her family members; the older persons' "group"; and the NPO itself. If, for discussion's sake, we indeed assume that the four different "actors" are all "clients," a complex relationship is formed, which demands ethical clarification. Moreover, in reality, only two "clients" might be physically present—the direct applicant and his or her family members. One perpetually absent client is the group of elders (its authentic representative is unclear and its actual definition is complex). Another "present-absent"" client is the NPO—its members, ideology, and spirit—which are usually not personally involved in the specific case.

Here, therefore, the authors would argue that the ""who is the client" dilemma—in the context of NPO representation—is "quadrupled." It is quadrupled into a potentially genuine ethical conflict, against a background of multiple loyalties, when, in order to resolve these loyalties, the lawyer must identify who is the "real" client. As opposed to the dilemma accepted in the private sector, where the lawyer must "choose" or "decide" who is the client, we would argue that in the case of NPO, the "real" client is a single entity, as all the four "different" clients are inseparable.

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[86] The professional "loyalty" to the culture, values, and organizational spirit of the NPO may transform the lawyer's perspective, as to view its employer (the NPO) as a "client" whose interests it needs to serve.

This "unifying" characteristic of the potentially four different clients is part of the essence of lawyering for social change. In representing the model whose goal is social change, the individual client is not simply a "client," but rather he or she becomes a type of "strategic partner" for accomplishing the broad social goal. The client is not "led" and the lawyer is not ideologically or morally indifferent to the client's legal issue.[87] There is uniformity of interests and the professional issue becomes, to some extent, the personal issue of the representing lawyer.[88] The group, as a potential client, dictates the goal to the lawyer, as interpreted by the lawyer according to his or her acquaintance with the group.[89] The NPO dictates the lawyer's strategy and the individual client dictates the narrow legal goal. The lawyer is required to integrate ideologies and interests but the balance is left to his or her discretion in the absence of general guidelines.

Going back to the findings of this study, the above model may shed light on the way Israeli NPOs described their experience of this ethical dilemma. For example, in the case of Ken LaZaken and LSE, applicants were not generally recognized as "clients." The interviewees did not mention the "client"" group or any professional obligations toward it, and neither did they refer to the NPO as a "client." The lawyers indicated no conflict with the client's family and the findings showed that in practice, the lawyers expressed no reason to withhold information about the elder from the family (except in conspicuous cases of a potential conflict of interest between the applicant's family and the elder).

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[87] Fried Charles, *Lawyer as Friend: The Moral Foundations of the Lawyer-Client Relation*, 85 YALE L.J. 1060, 1066 (1976).

[88] YSAIAH ROSS, ETHICS IN LAW: LAWYER'S RESPONSIBILITY AND ACCOUNTABILITY IN AUSTRALIA 37 (3d ed. 2001).

[89] *See* ROSS, *supra* note 89*; see generally* THOMAS L. SHAFFER, FAITH AND THE PROFESSION 200–06, 223–24 (1986).

To summarize the issue of the place of the client when represented by the NPO, the findings show that all three NPOs referred to the client as an "applicant" and not as a client. The participating lawyers sometimes expressed surprise when the question was posed during the interview and asked "to think for a moment" to reconstruct and provide a response. This may seem surprising. However, if we adopt the "unifying" notion, which, in the context of non-for-profit organizations, provides legal representation of older clients (and their family members), as part of a social goal to improve the "groups" interest—which is also the NPOs ideology and justification of existence—then indeed there is no "dilemma" of "who is the client." The client is a single, unified abstract entity, which encompasses all four "different" potential clients.

C. Loyalty Dilemmas: From the Triple Challenge to the Quintuple Challenge

The ethical issue surrounding the professional loyalty of the NPOs' lawyers goes beyond the question of "who is the client." Recognizing the identity of the client only answers the question regarding the lawyer's duty of loyalty to the "client." However, lawyers have professional duties beyond their duties to their clients.[90] Specifically, within the context of lawyers working in NPOs, one may argue that they have at least three immediate subjects to which they need to show different degrees of professional loyalty. Their loyalty to the individual client has to be absolute in terms of the rules of professional responsibility, as this is the person for whom they provide the legal services. Their loyalty to the group of older persons is fitting as representatives of an NPO that promotes elder issues.[91] Their loyalty to the NPO also means loyalty to its direction and ideology.

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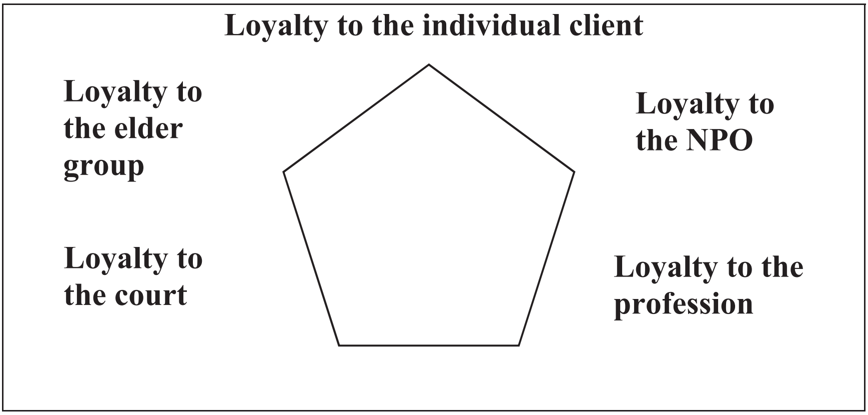
[90] According to Israeli legal tradition, lawyers have ethical duties not only to their clients, but also to the courts and to society.

[91] Neta Ziv, *Lawyers Talking Rights and Clients Breaking Rules*, 11 CLINICAL L. REV. 209, 224 n.73 (2004).

As discussed above, within the dilemma around "who is the client," this triple loyalty can be resolved within a unifying framework. However, beyond the triple conflict of loyalty between the various clients, the NPO lawyers have an even wider range of professional loyalties. Under Israeli law and according to the rules of professional liability, lawyers in Israel must be loyal also to the court as well as to the profession. Hence, mapping the *broad conflict of loyalty* can produce the following quintuple challenge, as presented in the following figure:

Figure 1: The Dilemma of Loyalty—The Quintuple Challenge



As can be seen above, lawyers in NPOs representing older persons are potentially caught between five different loyalties. Despite this complexity of professional loyalties, no legal guideline exists in Israel for coping with the narrow conflict of loyalties (between "clients") or the broad conflict of loyalties (including all the different loyalties) or even to identify the objects of the loyalties. However, since the conflict of loyalties is integral to representation by a not-for-profit organization, it seems that the rules of this issue must be adapted to enable basic direction or a decision-making system in case of a clash. Today, the balance, and its actual existence, is left to the NPO lawyers.[92]

According to Prof. Neta Ziv, when a concrete file has implications for a certain population, then there is room to examine the interests of the population that might be influenced by the representation. This type of test actually broadens the loyalties to an additional group and the subgroups within it, starting from the public in general and the individual stakeholder groups, to groups that might be influenced by it. Therefore, the loyalty conflict can be described, basically, through a quintuple structure, which is changeable, dynamic, and expanding, according to the circumstances and according to the lawyer's personal decision-making method.

It seems that to cope with the conflict, there is room, first and foremost, to act with transparency; to bring the potential conflict and its different aspects to the surface and to present it to the individual client, and even to provoke a discussion on the issue within the NPO. Within this discussion, broad ethical considerations and professional obligations can be made only by sharing information and the process with the client. In addition, it is important to ascertain that the legal goal is consistent with the best interest of the "client" (as was defined in the previous section). However, it is fitting that this aspect also be settled by an ethical code for representing NPO lawyers, which, among other things, would include clarification of the lawyers' loyalties and professional obligation on three parameters: transparency, full disclosure, and informed consent of the applicant.

VI. CONCLUSION

The study presented in this Article was designed to examine the uniqueness of the ethical dilemmas in legal representation

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[92] *See, e.g.,* MD. LAWYER'S R. PROF'L CONDUCT 1.7.

through NPOs, while investigating the case of NPOs for consulting and representation of elder clients, and to investigate the degree of the lawyers' awareness of the dilemmas and of how to cope with them. The study identified unique ethical dilemmas characteristic of representation through elder NPOs, such as the screening dilemma, the funding dilemma, and the dilemma of representing the group interest.

At least under Israeli law, the place of individual elders who apply to the NPO to receive legal services has not yet been ethically regularized. No examination has yet been made of the professional liability toward them and their place among other potential clients. There seems to be room to examine the essence of the professional relationship with the elder and to redefine the lawyer-client relationship in cases of representation, or even of only consulting, within the framework of the NPOs, to outline a professional framework for action and an ethical framework for decision-making and direction in cases of ethical conflict. Explicit definition as a client even in a framework of legal services, which includes only consulting, will officially impose professional obligations on the NPO lawyers regarding the client and as part of the professional liability and not only regarding the professional ethics.

The NPOs providing legal services to older persons in Israel are a major authority in mapping social change in everything concerning the rights of older persons. They are the specialized actors who are focused on legal issues of elders in Israel. Nevertheless, the research shows that ethical dilemmas were left to be solved internally. Despite the ongoing encounter with elder issues, no internal guidelines were found for making ethical decisions, which are made based on practical constraints (such as the issue of "who is the client"), to produce the most efficient response to elder issues. This reinforces the conclusion that sections of the professional liability rules need updating and redefining to establish a concrete framework for decision-making among lawyers in general and in NPOs in particular. This is necessary in the unique context of representing older clients as individuals and as a group because of the uniqueness of the representation and the challenges that arise in the legal services that they provide.

Finally, it should be noted that legal representation through a not-for-profit organization will always be different and unique compared to private (for-profit) representation. The NPOs' legal representation is much more complex, complicated, and raises unique ethical issues, as were found in this study. The whole issue of the "group's interest," where in reality the members of the group are passive regarding a final legal arrangement or decision, even though the group issue is at the heart of the action, is an ethical dilemma noted in this study.[93] The whole issue of the NPO's ideology, funding, and internal processes, are also different. And finally, the fact that existing rules of professional conduct do not recognize or address the situation in which lawyers represent an artificial "unified entity," which includes not only the older person or his/her family members, but also the whole "group" of elders, is also an ethical issue worth noting.[94] Recognizing the uniqueness of these ethical dilemmas is the first step to attempt to shape the rules which will enable to resolve them.

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[93] G.C. HAZARD ET AL., THE LAW AND ETHICS OF LAWYERING 2–3 (3d ed. 1999).

[94] *See* MODEL R. PROF'L CONDUCT 1.8.

REVISING THE REQUIREMENT OF INFORMED CONSENT IN AN ERA OF PRIVATIZATION, MANAGED CARE AND ACOS: IMPLICATIONS FOR BIOETHICS AND THE CONNECTION BETWEEN LAW AND ETHICS

Daniel Sperling[*]

I. INTRODUCTION

The ethical requirement of informed consent is one of the most fundamental maxims in biomedical ethics, protecting the autonomy of the patient/human subject. While this requirement reflects an elementary moral duty towards persons in a clinical setting, it was also developed in case law in line with a patient-centered approach in a dyadic relationship. In Jay Katz's words, the doctrine of informed consent "constituted a radical break with the silence that had been the hallmark of physician-patient interactions throughout the ages."[1]

Although, prior to the mid-twentieth century, the moral warrant for the preliminary idea of informed consent was justified under the principle of beneficence—usually understood and defined by professionals as medical benefits—from this period onward the evolving concept of informed consent was seen as deriving from the principles of autonomy and respect for persons.[2] This re-

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[*] Daniel Sperling is a senior lecturer in bioethics and health law at the University of Haifa and teaches at the Department of Nursing and the Faculty of Law. This Article is the product of my research at the Peterie-Flom Center for Health Law Policy, Biotechnology and Bioethics at Harvard Law School during my sabbatical in 2013. I am grateful for the academic support and fruitful comments of the Center's staff and visitors when I presented parts of this Article at Harvard. I am also indebted to Haavi Morreim, Glenn Cohen, and Mark Hall for insightful comments on early drafts.

[1] Jay Katz, *Informed Consent–Must It Remain a Fairy Tale?*, 10 J. CONTEMP. HEALTH L. & POL'Y 69, 72 (1993).

[2] Becky C. White & Joel Zimbelman, *Abandoning Informed Consent: An Idea Whose Time Has Not Yet Come*, 23 J. MED. & PHIL. 477, 478 (1998).

conceptualization of informed consent occurred along with a shift in the moral weight given to this issue. It was no longer seen as optional or conceived as a simple agreement between physicians and patients, but became mandatory and reflected a more complex procedure of allowing patients to participate in the choice of their course of treatment.[3] Moreover, informed consent was no longer merely a moral principle, but a legal requirement strongly enforced by the courts, especially through the language of rights, along with a more general influence of law on bioethics.[4]

However, with the increased realization that health care is delivered in a complex system that changes over time, and the prominence of managed care organizations in some places, starting in the mid-1970s in the United States,[5] the emergence of Accountable Care Organizations (ACOs),[6] new regulations and policies for national open payment programs under the Patient Protection and Affordable Care Act, and the rise of privatization in social health systems such as those in Israel,[7] the legal discussion of informed consent is starting to change. Gradually, the extent of the physician's duty to disclose information relevant to the patient's decision has been limited by new factors such as treatment setting, source of payment, financial incentives for the physician, cost and time constraints, and the broader context of the health care system.

This Article carefully evaluates the impact of what the Author regards as significant changes to the doctrine of informed consent in bioethical literature, and uses this test case to make more

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[3] *Id.*

[4] Daniel Sperling, *Law and Bioethics: A Rights-Based Relationship and Its Troubling Implications*, 11 CURRENT LEGAL PROBS.52, 65 (2008).

[5] ROBERT G. SHOULDICE, INTRODUCTION TO MANAGED CARE: HEALTH MAINTENANCE ORGANIZATIONS, PREFERRED PROVIDER ORGANIZATIONS, AND COMPETITIVE MEDICAL PLANS 25–29 (rev. ed. 1991).

[6] Diane R. Rittenhouse et al., *Primary Care and Accountable Care–Two Essential Elements of Delivery-System Reform*, 361 NEW ENG. J. MED. 2301, 2301–03 (2009).

[7] *See generally* Aeyal Gross, *The Right to Health in Israel Between Solidarity and Neoliberalism*, in THE RIGHT TO HEALTH AT THE PUBLIC/PRIVATE DIVIDE: A GLOBAL COMPARATIVE STUDY 159, 159–87 (Colleen M. Flood & Aeyal Gross eds., 2014).

general observations about the relationship between law and bioethics.[8] To make a universal claim about the proposed and recent changes to the doctrine of informed consent in the light of new organizational changes, the Article begins by describing the recent developments in the organization, financing and delivery of services in two different health care systems: the one in the United States and the one in Israel. After critically describing, examining, and evaluating the legal revisions recently made or proposed to the doctrine of informed consent in light of these organizational changes, the Author offers a prima facie ethical analysis of these changes. The Author then argues that, surprisingly, the bioethical literature has shown very little interest in these important changes, in spite of their expected implications for patients, doctors, and the health system more generally. Thus, reviewing the literature suggests that there are hardly any articles or books discussing these fundamental changes or coming in the wake of the scholarly suggestions made in this respect. The Author then proposes two sets of reasons for this surprising phenomenon. The first has to do with changes in the managed care system, specifically the managed care backlash. The second consists of reasons that involve the connection between ethics and law. These include four sub-suggestions: first, legal changes are of no real interest to ethics; second, legal changes are unfamiliar to ethicists; third, informed consent has different rationales in law and ethics; fourth, informed consent is conceptualized differently in law and ethics due to the distinction between positive and negative rights. The Author concludes this discussion by arguing that while all or some of these explanations may work well, they do not provide a convincing answer as to why changes in the most prominent doctrine in bioethics have received so little attention and discussion in ethical literature.

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[8] *See generally* Sperling, *supra* note 4.

The Author then puts forward a stronger claim by discussing the concept of "the money taboo" and argues that the lack of interest in legal changes in the doctrine of informed consent derives from doctors' and patients' reluctance to discuss money, and the formation of the bioethical discussion in a way that preserves and perpetuates this reluctance. In the last part of the Article, the Author supports this claim by reviewing some of the major bibliographical sources in which the money taboo can be observed. These sources are grouped into three major areas: the question of whether health and health care can or should be commodities; the idea of trust in medicine; and physicians' conflicts of interest, and possible corruption. The Article concludes with some remarks and observations on the connection between medical law and bioethics and the effect that money in medicine might have on ethical discussions.

II. THE LEGAL DOCTRINE OF INFORMED CONSENT

It is no exaggeration to argue that the legal doctrine of informed consent is one of the most influential interventions of law in bioethical issues. There are several explanations for the way the legal requirement of informed consent is constituted. In *Canterbury v. Spence*,[9] the court ruled that respect for the patient's right of self-determination demands "a standard set by law for physicians rather than one which physicians may or may not impose upon themselves."[10] In addition, as argued by Carl Schneider, the law of informed consent should be aimed not only at remedying specific failures to inform patients but also at fundamentally reforming the relationship between doctors and patients.[11] Finally, the law of informed consent has provided authorization and thus relieves physicians of potential legal liability.[12]

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[9] Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972).

[10] *Id.* at 784.

[11] Carl E. Schneider, *Bioethics in the Language of the Law*, 24 HASTINGS CTR. REP., July–Aug. 1994, at 16, 18.

[12] Susan M. Wolf, *Toward a Systematic Theory of Informed Consent in Managed Care*, 35 HOUS. L. REV. 1631, 1664 (1999).

The legal doctrine of informed consent includes the duty to apprise the patient of his or her condition, the nature of the proposed treatment, the benefits reasonably to be expected from a proposed treatment, as well as its material risks and dangers, and the alternative treatments, as well as the risks and benefits of each alternative.[13] Exceptions to the requirement of informed consent hold when additional procedures are necessary for completing the initial treatment for which consent was obtained,[14] in emergency situations when one can presume that the patient would have given consent to protect her life (unless the patient initially refused to give consent), and when giving complete information would be harmful to the patient.[15]

An action based on lack of informed consent is regarded in the law as battery.[16] The doctrine of battery protects a patient's bodily integrity and requires showing only that the patient was not informed about the medical touching.[17] The plaintiff does not need to show he or she suffered physical injury as a result of the breach of informed consent.[18]

However, once the requirement of informed consent became popular and accepted, it was reformulated in a way that failing to obtain informed consent now constitutes negligence.[19] In order to

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[13] BARRY D. ALEXANDER ET AL., FUNDAMENTALS OF HEALTH LAW 63 (5th ed. 2011).

[14] Although some cases require separate consent if additional procedures are needed.

[15] However, the harmful information exception has rarely been upheld. Other exceptions may include waiver of consent, incompetence (which arguably may not be an "exception") and mandatory treatment, e.g., in a public health setting. *See generally* Est. of Leach v. Shapiro, 469 N.E.2d 1047 (Ohio Ct. App. 1984); Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972).

[16] *See, e.g.*, MARK A. HALL ET AL., HEALTH CARE LAW AND ETHICS IN A NUTSHELL 126 (3d ed. 2011).

[17] Katz*, supra* note 1, at 78.

[18] Osborne M. Reynolds, Jr., *Tortious Battery: Is "I Didn't Mean Any Harm" Relevant?*, 37 OKLA. L. REV. 717, 717 n.1 (1984).

[19] Paula Walter, *The Doctrine of Informed Consent: To Inform or Not to Inform?*, 71 St. John's L. Rev. 543, 552 (1997).

argue the case successfully, a patient must show that "(1) the course of treatment followed carried an undisclosed risk; (2) the physician's non-disclosure of that risk breached the applicable standard of care owed to the patient; and (3) the undisclosed risk caused the patient injury, in both a physical sense (by actualizing the risk) and a behavioral sense (in that, with proper disclosure, the patient would have made a different treatment choice, thus avoiding the harm)."[20]

Two competing tests developed under the law of torts have been offered in case law to determine the extent of the physician's duty to disclose information to the patient.[21] While courts and legislation in a majority of the states in the United States have ruled that the information to be disclosed to the patient should be in accordance with accepted medical practice,[22] English, Canadian, and Israeli courts have demanded more of physicians and held that such information should apply to the needs and expectations of a reasonable patient.[23]

Various rationales have been used for the doctrine of informed consent. First and foremost, because informed consent promotes and enhances respect for the patient's autonomy, it is justified by the intrinsic value of personal autonomy.[24] The right to choose and determine one's own life and make decisions concerning one's body and self promotes autonomy.[25] Providing all necessary information for the patient's medical decision-making promotes authenticity, decision-making competence, and effectiveness of

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[20] HALL ET AL., *supra* note 16, at 126.

[21] *See, e.g., id.* at 127–30.

[22] *See* FLA. STAT. § 766.103(3)(a)(1) (2018); N.Y. PUB. HEALTH LAW § 2805-D (McKinney 2018); Ketchup v. Howard, 543 S.E.2d 371, 377 (Ga. Ct. App. 2000) (surveying states' laws regarding informed consent).

[23] Pearce v. United Bristol Healthcare NHS Trust [1999] PIQR P 53; Reibl v. Hughes [1980] 2 S.C.R. 880; CA 6153/97 Shtandel v. Sade; CA 4960/04 Sidi v. Clalit Sickness Fund; CA 1303/09 Kadosh v. Bikur Cholim Hospital et al.

[24] RUTH R. FADEN ET AL., A HISTORY AND THEORY OF INFORMED CONSENT 16–19 (1986); White & Zimbelman, *supra* note 2, at 491.

[25] White & Zimbelman, *supra* note 2, at 491.

decision-making, and controls the degree to which the person decides and acts on his or her own preferences and has them satisfied—all of which constitute the patient's autonomy.[26] Second, informed consent provides persons with strict control of access to their bodies, determining who can touch them, and on what conditions they may be touched.[27] The doctrine is part of the moral obligation not to intrude on a person's body or thoughts, which derives from the more fundamental duty to respect persons.[28] Third, informed consent guarantees that both the patient and physician will retain their moral integrity and will be equally responsible decision-making partners.[29] The physician-patient relationship is inherently asymmetrical, because patients are physically and emotionally dependent on their physicians. The field of medicine, the way its concepts are structured and the meaning of its terms are mostly unfamiliar to the patients, however literate they might be. Moreover, patients' dependency on their physicians is heightened by pain, anxiety, fear, shame and sense of inferiority as a result of sickness. In the face of this imbalance in authority and knowledge, the doctrine of informed consent obliges physicians to arm patients with the information needed to understand and participate effectively in their own care.

A fourth rationale for the doctrine is consequentialist.[30] According to this rationale, providing full and necessary

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[26] Lars Sandman & Christian Munthe, *Shared Decision-Making and Patient Autonomy*, 30 THEORETICAL MEDICINE & BIOETHICS 289, 292–93 (2009). *Compare* JAMES TAYLOR, PRACTICAL AUTONOMY AND BIOETHICS 130–31 (2009) (stating that informed consent is not necessary to autonomy), *with* Natalie Stoljar, *Informed Consent and Relational Conceptions of Autonomy*, 36 J. MED & PHILOSOPHY 375, 375 (2011) (arguing that informed consent is not sufficient for autonomy).

[27] White & Zimbleman, *supra* note 2, at 491.

[28] *Id*. at 478.

[29] Robert M. Veatch, *Models for Ethical Medicine in a Revolutionary Age*, 2 HASTINGS CTR. REP., June 1972, at 5, 6.

[30] White & Zimbleman, *supra* note 2, at 491–92.

information to the patient puts his or her in a position in which he or she can make the best medical decision for him- or herself not just by having more information pertinent to the decision, but also by balancing what the patient has accumulated on his or her own, e.g., through an Internet search, with more specific and responsible clinical information focused on her medical condition, history and other important factors concerning her situation.[31] Informed consent also enhances the communication between physician and patient, thereby improving the flow of information from the patient to the physician and thus paving the way for a better course of action.[32]

Finally, the duty to disclose full information encourages physicians to reflect on their medical plans and the alternatives to them, serving as an important way of influencing their professional decisions. Fifth, the requirement of informed consent greatly improves physician-patient dialogue and the whole process of treatment. As such, it fosters patients' trust, which is so important to this sort of relationship.[33] Lastly, people commonly tend to subvert the interests of others and their duties to them in the pursuit of their own goals and interests.[34] In the medical setting, this is often done unintentionally and without full awareness.[35] According to this sixth rationale, because the principle of informed consent encourages doctors to consider the interests of their patients and empower the latter with the right to participate in decision-making, it serves to

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[31] *See generally* STEPHEN WEAR, INFORMED CONSENT: PATIENT AUTONOMY AND PHYSICIAN BENEFICENCE WITHIN HEALTH CARE (2d ed. 1998) (discussing how patients, despite strides made in the medical consumer movement amoung the helathy and educated, still tend to turn to their physicians for their expertise and reassurance and seek to be reassured, not educated and forced to make decisions on matters that they, the patients, are not familiar).

[32] See generally James L. Bernat & Lynn M. Peterson, *Patient-Centered Informed Consent in Surgical Practice*, 141 ARCHIVES OF SURGERY 86, 87 (2006) (concluding that "consent is best conceptualized as shared decision making with patients or their surrogates"); David S. Brody et al., *Patient Perception of Involvement in Medical Care: Relationship to Illness Attitudes and Outcomes*, 4 J. GEN. INTERNAL MED. 506, 506 (1989) (concluding that "patients' perceptions about their involvement in care appeared to be related to their attitudes about their illness as well as to recovery").

[33] MARK A. HALL, MAKING MEDICAL SPENDING DECISIONS: THE LAW, ETHICS, AND ECONOMICS OF RATIONING MECHANISMS 205 (1997).

[34] White & Zimbleman, *supra* note 2, at 492.

[35] Maxwell J. Mehlman, *Dishonest Medical Mistakes*, 59 VAND. L. REV. 1137, 1140 (2006).

constrain or counteract health providers' tendencies to ignore or subvert patients' interests, thus protecting the latter from being harmed.[36]

However, in recent years, there has been a gradual change in the legal doctrine of informed consent. This is a direct response to dramatic transformations in the organization and provision of health care. The next part focuses on two very different health systems, the American one and the Israeli one, to argue that despite the differences between them—privatization of health services in the former and the rise of managed care and accountable care organizations in the latter—there have been substantial revisions to the requirement of informed consent and the setting in which this requirement is actualized in both cases.

III. ORGANIZATIONAL AND FINANCIAL TRANSFORMATIONS OF THE HEALTH SYSTEM

A. Israeli Health System

Since the enactment of the National Health Insurance Act in 1995, all Israeli residents have been entitled to publicly funded health insurance.[37] Such insurance is mostly defined by a comprehensive, uniform medical package of health care services that is updated once a year.[38] Health care services are covered by an income-based health insurance tax with reduced rates for the poor and the elderly, combined with direct government contributions.[39] Most of these services are provided by four health funds that act

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[36] White & Zimbelman, *supra* note 2, at 492.

[37] BRUCE ROSEN & HADAR SAMUEL, ISRAEL: HEALTH SYSTEM REVIEW 15 (2009).

[38] Revital Gross et al., *Reforming the Israeli Health System: Findings of a 3-Year Evaluation*, 56 HEALTH POL'Y 1, 8 (2001).

[39] *Id.* at 3, 6.

under regulated competition.[40] Public capitation payments to the health funds, based mainly on the age of the insured, cover the major benefits included in the medical package that are specified by law.[41] Under the Israeli health system, every Israeli citizen has a right to choose his or her health fund and his or her primary physician within each fund, and the funds must accept anyone who requests to join them.[42] Citizens can also switch their health fund up to six times a year.[43]

In addition to the services included in the national medical package, which every health fund has a duty to provide with no or minimal co-payments, citizens may purchase complementary health insurance provided by the four funds, which are legally regulated and controlled by the Ministry of Health.[44] In addition, citizens may purchase a private health insurance program from any commercial insurance company to cover services that are not included in the basic or complementary programs, or that are included but for which the private insurance company can offer better conditions.[45]

However, in the past two decades, there has been a gradual reduction in state expenditure for health, along with an increase in private financing (e.g., out of pocket payments, commercial health insurance, and supplemental health insurance).[46] Thus, unlike the situation in most Organization for Economic Co-operation and Development (OECD) countries,[47] where private per capita

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[40] *Id*. at 4, 11.
[41] ROSEN & SAMUEL, *supra* note 37, at 11.
[42] *Id*.
[43] Daniel Sperling, *Needs, Expectations, and Public Knowledge Concerning Services Outside the Meidcal Basket: A Lesson from Israel*, 117 HEALTH POL'Y 117, 249 (214).
[44] *Id*.
[45] There are also exceptional situations in which citizens can apply to the health funds to receive, under public financing, drugs and services which are not included in the health package or that are included in the package but only for other medical conditions. *See generally id.* at 247.
[46] Giora Kaplan et al., *Supplementary Health Insurance From the Consumers Point of View: Are Israelis Consumers Doing an Informed Rational Choice When Purchasing Supplementary Health Insurance?* 121 HEALTH POL'Y 708, 709 (2017).
[47] Currently, thirty-five member countries belong to the Organization for Economic Co-operation and Development, whose aim is to promote policies for improving the economic and social well-being of

spending for health has declined or risen only slightly,[48] the proportion of the latter in Israel showed a significant growth from 30% in 1995 to 35.6% in 2000, to 37.1% in 2005 and 38.1% in 2009.[49] In addition to an increase in the number of private hospitals and clinics, public hospitals and health funds have been offering more private services, such as imaging or diagnostic institutes, institutes for cosmetic surgery, centers for alternative medicine, etc. Complementary health insurance offered for an extra fee by health funds is not considered discriminatory among patients with regard to accessing the most essential health services.[50] Commercial health insurance is on the rise.[51] Moreover, it is well known that in recent years the health care industry in Israel has adopted a business culture in which health and health care are considered a commodity and curbing costs is one of the major goals,[52] reinforcing aspects of commercialization.[53] These changes have occurred along with a growth of 50% in the number of firms belonging to the health care field, an increase of almost 30% in the number of people employed in health care companies, and a growth of twenty-five-fold in the sales volume in the health care field from 1979 to 1999, suggesting the dynamism of the health care sector in Israel's economy.[54] More generally, the changes reflect a great "emphasis on individual legal

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people around the world. *Organisation for Economic Co-Operation and Development (OECD)*, OECD.ORG, http://www.oecd.org/about/ (last visited Dec. 17, 2018).

[48] Sperling, *supra* note 43, at 255.

[49] Cent. Bureau of Statistics, *National Expenditure on Health, by Financing Sector 2016–2000*, http://www.cbs.gov.il/hodaot2017n/08_17_244t3.pdf (last visited Dec. 17, 2018).

[50] Aeyal Gross, *Is There a Human Right to Private Health Care?*, 41 J.L. MED. & ETHICS 138, 142 (2013).

[51] Marc A. Cohen & Tamara Barnea, *Private Outlets for Public Limitations: The Rise of Commercial Health Insurance in Israel*, 17 J. HEALTH POL. POL'Y & L. 783, 784 (1992).

[52] Dani Filc, *The Health Business Under Neo-Liberalism: The Israeli Case*, 25 CRITICAL SOC. POL'Y 180, 184 (2005).

[53] Ronni Gamzu & Bruce Rosen, *The Commercial Challenge to Israeli Health Care and How It Can Be Addressed* (unpublished paper; on file with Author).

[54] Filc, *supra* note 52, at 185.

rights, entrepreneurship and personal wealth,"[55] promoting neo-liberal individualism.[56]

B. The American Health System

Starting in the 1970s, the American health system has shifted from a "fee for service" basis of health care provision to a managed care model with health maintenance organizations (HMOs),[57] whose main defining feature is the receipt of a fixed fee for each patient enrolled under the terms of a contract to provide specified health care, if needed, regardless of the extent of this care (the "capitation payment").[58] The term "health maintenance organization," coined by health policy analyst Paul Ellwood, is meant to emphasize the positive incentive to keep patients healthy rather than the incentives under the fee-for-service payment which pay doctors more the sicker their patients are.[59] Under this scheme, HMOs profit by treating less rather than more. These changes occurred because fee-for-service, which was and still is the biggest financial incentive for physicians, encouraged them to provide unnecessary treatments.[60] Moreover, it led to a sharp move from a clear separation between the entities that pay for health care directly to the person and entities delivering it through a combined method of financing and delivering care, so that now physicians are both caregivers and cost

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[55] Guy I. Seidman, *Is a Flat-Line a Good Thing? On the Privatization of Israel's Health Care System*, 36 AM. J.L. & MED. 452, 467 (2010).

[56] Ran Hirschl, *Israel's 'Constitutional Revolution': The Legal Interpretation of Entrenched Civil Liberties in an Emerging Neo-Liberal Economic Order*, 46 AM. J. COMP. L. 427, 428 (1998).

[57] Eric R. Wagner & Peter R. Kongstvedt, *Types of Managed Care Organizations and Integrated Health Care Delivery Systems*, in PETER R. KONGSTVEDT, ESSENTIALS OF MANAGED HEALTH CARE, ch. 2 (6th ed., 2013), *available at* https://pdfs.semanticscholar.org/d4d4/aa421204373dafd25d4787bdb61b4cbfd26c.pdf.

[58] SHOULDICE, *supra* note 5. The HMO model accounts for over half of all private insurance and is also becoming more prominent in Medicare and Medicaid. HALL et al., *supra* note 16, at 70.

[59] *Id.* at 68.

[60] Current estimates show that about 30% of all tests and treatments done are unnecessary, amounting to 750 billion dollars every year. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America 2012*, THE INST. OF MED. 2 (Sept. 2012), www.iom.edu/Reports/2012/Best-Care-at-Lower-Cost-The-Path-to-Continuously-Learning-Health-Care-in-America.aspx.

managers.[61] Under the managed care plans through which patients are insured, a patient must choose a primary care physician who serves as a "gatekeeper" responsible for deciding whether the patient requires tests, inpatient hospitalization, or a referral to a specialist.[62] The HMO usually keeps 20% of the capitation payment it receives and then splits the remainder between the contracting hospitals and the physicians.[63] For example, "each primary care provider might receive 40% of the capitation payment for each patient for which she is responsible, and use it to cover all physician services, pharmacy costs, and the cost of the specialists to whom they refer their patients."[64] "[T]he remaining 40% might be set aside in a pool to pay for hospitalization costs" authorized by the physicians.[65]

Under an alternative approach known as "global capitation," a large multi-specialty physician group receives 80% of the capitation payment and then contracts downstream with hospitals and specialists.[66] At times, the gatekeeper is paid a bonus for controlling referrals or decreasing utilization of health services more generally and is penalized for excessive treatment.[67] Moreover, like other risk-bearing organizations, HMOs take steps to control risks, including making coverage determinations; scrutinizing requested services against the contract; issuing general guidelines for their physicians about appropriate levels of care; reviewing specific

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[61] Deven C. McGraw, *Financial Incentives to Limit Services: Should Physicians be Required to Disclose These to Patients*, 83 GEO. L.J. 1821, 1821 (1995*). See also generally* Jacob S. Hacker & Theodore R. Marmor, *How Not to Think About "Managed Care"*, 32 U. MICH. J.L. REFORM 661, 674–75 (1999).

[62] McGraw, *supra* note 61, at 1827.

[63] HALL et al., *supra* note 16, at 69.

[64] *Id*.

[65] *Id*.

[66] *Id*. However, these arrangements were actually quite short-lived, as they failed to spend adequately for infrastructure.

[67] McGraw, *supra* note 61, at 1828.

treatment decisions by a person other than the treating physician; and approving in advance some types of care, keyed to standards of medical necessity or the reasonableness of the proposed treatment.[68]

However, as evidence has accumulated indicating that capitated providers practice more conservative care,[69] since many provider organizations have suffered significant financial loss under capitation,[70] and also due to consumer backlash against managed care restrictions,[71] the prevalence of capitation contracts decreased after the mid-1990s. Yet, due to this change, the need to control medical spending has become more critical and new attention has been focused on the role of the fee-for-services system in the growth of health care spending in recent years.[72]

As a result of this increased growth, which has been attributed to an increase in the delivery of services under the fee-for-services payment system that regained its power following the managed care backlash, the Centers for Medicare and Medicaid Services (CMS) has recently established a Medicare Shared Savings Program (MSSP) to facilitate coordination and cooperation among providers to improve the quality of care for Medicare fee-for-service beneficiaries and reduce costs.[73] Eligible providers, hospitals and health suppliers may participate in this program by creating an Accountable Care Organization (ACO) that functions under a

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[68] Pegram v. Herdrich, 530 U.S. 211, 219 (2000).

[69] Alan L. Hillman et al., *How do Financial Incentives Affect Physicians' Clinical Decisions and the Financial Performance of Health Maintenance Organizations?*, 321 NEW ENG. J. MED. 86, 90 (1989); Jason Shafrin, *Operating on Commission: Analyzing How Physician Financial Incentives Affect Surgery Rates*, 19 HEALTH ECON. 562, 563 (2008); Sally C. Stearns et al., *Physician Responses to Fee-for-Service and Capitation Payment*, 29 INQUIRY 416, 420 (1992).

[70] James C. Robinson, *The End of Managed Care*, 285 J. AM. MED. ASS'N. 2622, 2624 (2001).

[71] David Mechanic, *The Managed Care Backlash: Perception and Rhetoric in Health Care Policy and the Potential for Health Care Reform*, 79 MILBANK Q. 35, 37 (2001).

[72] Michael E. Chernew et al., *Private-Payer Innovation in Massachusetts: The 'Alternative Quality Contract'*, 30 HEALTH AFF. 51, 52 (2011).

[73] Ctrs. for Medicare & Medicaid Servs., *Shared Savings Program*, CMS.gov, https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/sharedsavingsprogram/about.html (last modified Mar. 27, 2018, 11:54 a.m.).

common set of delivery and financing principles.[74] There are a number of requirements for participating in the program, including a three-year participation commitment, a formal legal structure for receiving and distributing shared savings, "a sufficient number of primary care physicians to treat at least 5,000 Medicare beneficiaries," a procedure for reporting quality and cost measures, and a procedure for promoting evidence-based medicine.[75] CMS rewards ACOs that meet the quality performance standards only if the risk-adjusted-per-beneficiary expenditures are below the established benchmark.[76] Payment is made under two basic models.[77] In the first model, health care organizations are eligible to share in savings but bear no risk for losses for the first two years.[78] ACOs are entitled to receive about 50% of the savings accrued by the Medicare program after surpassing a fixed savings threshold.[79] In the second model, organizations take on risks from the beginning but receive a larger share of the savings, if this becomes available.[80] Participation in an ACO is voluntary for both providers and patients.[81] More stringent payment models,[82] such as the Alternative Quality Contract of Massachusetts's Blue Cross/Blue Shield in 2009,[83] require providers to share some or all of the risk if spending

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[74] *Id.*

[75] MANAGED CARE LITIGATION 13 (David M. Humiston et al. eds., 2d ed. 2013).

[76] *Id.*

[77] Bruce E. Landon, *Keeping Score Under a Global Payment System*, 366 NEW ENG. J. MED. 393, 394 (2012).

[78] *Id.*

[79] *Id.*

[80] *Id.*

[81] Ctrs. for Medicare & Medicaid Servs., CMS.GOV, *Accountable Care Organizations (ACOs): What Is an ACO?*, https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html (May 5, 2018, 2:52 p.m.).

[82] Chernew et al., *supra* note 72, at 53.

[83] *Id.*

exceeds the target.[84] If proved successful, these two models are likely to be followed by other commercial providers, as well as becoming a way of achieving a competitive advantage in the market through a collaborative effort to improve cost efficiency and quality.[85]

Although the American and Israeli systems differ dramatically, the recent transformations in health care delivery in both systems emphasize an evolving role of providers, that of gatekeepers and cost managers in a public setting like the Israeli health system, and of profit-oriented risk managers in the American scheme. The changes in both settings tend to promote market values of individualism, competition, entrepreneurship and personal wealth.[86]

Moreover, with the increased realization that health care is delivered in a complex and economizing system in an era when medical spending is on the rise, and with the prominence of managed care organizations, Alternative Quality Contracts in the United States and the rise of privatization in social health systems such as the one in Israel,[87] the legal discussion of informed consent is starting to change. Gradually, the extent of the physician's duty to disclose information relevant to the patient's decision has been limited by new factors such as treatment settings, payment

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[84] *Id.* For a more general discussion of physician payment reform legislation, see generally Mark McClellan et al., *Medicare Physician Payment Reform: Will 2014 Be the Fix for SGR?*, 311 J. AM. MED. ASS'N. 669 (2014).

[85] MANAGED CARE LITIGATION, *supra* note 75, at 13. For questions and considerations regarding ACOs' liability, see generally Harlan Benjamin Harvey & I. Glenn Cohen, *The Looming Threat of Liability for Accountable Care Organizations and What to Do About It*, 310 J. AM. MED. ASS'N. 141 (2013).

[86] For an excellent discussion of the evolution of medical commerce and physician entrepreneurship, see generally Marc A. Rodwin, *Medical Commerce, Physician Entrepreneurialism, and Conflicts of Interest*, 16 CAMBRIDGE Q. HEALTH CARE ETHICS 387 (2007).

[87] Part of this trend can also be explained by a decreasing protection of the right to healthcares services as well as significant reforms in the healthcare systems promoted by the Ministry of Finance. *See* Daniel Sperling & Nissim Cohen, *A Neo-Institutional Analysis of the Hidden Interaction Between Supreme Court and the Government: The Right to Healthcare in Israel as a Test-Case.* Israel Journal of Health Policy Research, 7(1), 71 doi: 10.1186/s13584-018-0261-9.).

providers, financial incentives for physicians, cost and time constraints, and the larger context of the health care system.

While informed consent had previously been discussed in the context of a dyadic relationship between physician and patient, funded by silent partners, a large number of players in complex relationships have come into play and shaped our understanding of the requirement of informed consent in the literature as well, especially the legal literature.[88] In this new age, a variety of mechanisms have been imposed to increase financial dependence among and within health systems. These include paying physicians only a certain amount per patient per time period; forcing the physician or the medical practice to pay for any cost overruns; withholding part of the physician's compensation depending on whether tests, hospitalizations, or other items fall below a certain benchmark; or tying bonus payments to organizational cost-cutting and financial success.[89] In this new reality, patients are also subscribers to specific coverage programs, which are specified in a contract with a managed care health plan and subject to various limits and other considerations.

As a result, the moral background of the doctrine of informed consent is no longer the fiduciary nature of the physician-patient relationship but the contractual obligations of the parties to the health plan specified in the contract. Conceptualizing the physician-patient relationship in a contractual setting resulted in claims, mainly by legal scholars, that a subscriber to a health plan could authorize her caregivers to make economizing decisions, and agree to limits on treatment and a rationing scheme, thereby

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[88] E. HAAVI MORREIM, BALANCING ACT: THE NEW MEDICAL ETHICS OF MEDICINE'S NEW ECONOMICS 141 (1991).

[89] Wolf, *supra* note 12, at 1645.

modifying the physician's duty to disclose off-plan treatment options and satisfying the requirement of informed consent in such a way that no treatment-specific disclosures are needed.[90] These changes to the doctrine of informed consent are discussed in the next part.

IV. EMPIRICAL SUPPORT FROM ISRAEL AND THE UNITED STATES

Recent case law in both Israel and the United States provides various examples of attempts to limit the scope and extent of the doctrine of informed consent in the light of new organizational changes in health systems. The following sections describe these attempts in both Israel and the United States.

A. Israel

In 2005, the Israeli Supreme Court delivered its decision in the *Sidi* case.[91] In this case, a wrongful birth action was brought against a health fund, a physician, and a diagnostic laboratory for not detecting a genetic malformation during pregnancy, resulting in a child born without his right hand and with severe breathing difficulties.[92] One of the arguments raised involved the fact that the treating physician should have notified the pregnant woman of an expanded ultrasound test offered in the private health sector that could have detected these defects.[93] Although the court held that there may be circumstances in which a duty to notify the prospective parents of diagnostic options offered in the private sector and even abroad should be recognized,[94] it ruled,

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[90] *See* Mark Hall, *Disclosing Rationing Decisions: A Reply to Paul S. Appelbaum*, MILBANK Q. 211, 214 (2014).

[91] CA 4960/0 Sidi v. Clalit Sickness Fund.

[92] *Id.*

[93] *Id.*

[94] *Id.* Compare this with the different approach taken in the United States. *See, e.g.,* Schiff v. Prados, 92 Cal. App. 4th 692, 707 (2001) (stating that informing patients of treatment alternatives that are legally available in another state, but not in California, is beyond what the law expects of physicians).

> When the court is about to evaluate the reasonable expectation of disclosure one should not ignore what professionals have to say as well as *the limited resources of the health system*, which is asked to provide for a large number of people…for this reasons it is ruled that physicians should not be required to provide explanations about remote and insignificant risks. The extent of disclosure should be narrowed to include only real risks which are substantial in a specific case.[95]

A more explicit argument was made in *Kadosh*, an Israeli Supreme Court case from 2011.[96] In this case, the plaintiff underwent a hysterectomy and surgery to lift her bladder in a special procedure called MMK, but contracted bowel adhesions and obstruction as a result of the surgery.[97] The plaintiff argued that she had not been informed about the risks for the specific harm she incurred.[98] Writing more generally about the doctrine of informed consent in Israeli law, the court stated that courts should take into consideration the viewpoint of professionals—the physicians—as well as the existence of *organizational constraints on the health system* when evaluating patients' reasonable expectations.[99] Thus, in *Kadosh*, the court explicitly connected the organization of health services with the doctrine of informed consent, suggesting a radical shift in the latter:

> The extent of the duty to disclose information to patients also derives from time and resources limitations, especially in a public health system. The

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[95] CA 4960/04 Sidi v. Clalit Sickness Fund.

[96] CA 1303/09 Kadosh v. Bikur Cholim Hospital.

[97] *Id.*

[98] *Id.*

[99] *Id.*

> time spent in the private health sector does not accord with the time constraints of the public health sector in Israel. Investing a great deal of time imparting information makes treatment more expensive. It may also come at the cost of time to be invested in other patients, thereby reducing the standard of care for those patients or reducing the number of patients receiving care. Using defensive medicine, physicians would treat fewer patients by providing them with more complete information since a physician might be found liable in tort even if only one patient had not received complete information.[100]

Furthermore, under recent Israeli law, judges began to refuse to apply the "reasonable patient" test to cases in which disclosing the information to patients who were not at risk was intended to predict or diagnose new diseases as opposed to offering active treatment.[101] The courts explained their reluctance to apply this test as due to the rapid technological development in prediction and diagnosis, and the high costs such tests might incur.[102] The courts also rejected the idea that there is a duty to disclose information about remote, irrelevant risks, partly because of the many resources that must be spent to do so.[103] In another leading case, the judges ruled that the principle of informed consent should be balanced with time constraints, especially when treatment is provided in a public health system.[104] In *Kadosh*, one of the Justices of the Supreme Court of Israel, , suggested shifting from an objective "reasonable

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[100] *Id.* (per Justice Amit decision).

[101] CA 434/94 Berman et al. v. Mor–Inst. Med. Info. Ltd. NA.

[102] However, a legal decision reported later applied the reasonable patient test to the prediction and diagnosis of diseases as well. CA 4960/04 Sidi v. Clalit Sickness Fund. In this case, however, Justice Naor ruled that this test should only be used when there is some indication of a medical need for an additional test, e.g., in case of suspicion of a specific disease CA1303/09 Kadosh v. Bikur Cholim Hosp.

[103] CA 7756/07 Gerstel v. Dan.

[104] CA 4960/04 Sidi v. Clalit Sickness Fund.

patient" test to a mixed test.[105] This would mean that the physician has a duty to disclose information that the *physician* knows or should have known would be considered important by a reasonable person in the patient's situation.[106] Deviating from the established "reasonable patient" test and adding the subjective evaluation of the physician was supported, *inter alia*, by the various limitations placed on physicians in the new reality.[107]

B. The United States

United States law has proceeded in the same direction as Israeli law. Recent legal changes to the doctrine of informed consent can be discussed in two categories: the settings upon and by which informed consent is exercised and those that affect the content of informed consent.

1. *Changes in the Settings of Informed Consent*

The courts and legislation in most of the states in the United States hold that physicians should disclose information to patients in accordance with accepted medical practice.[108] Importantly, one of the arguments in favor of a professional standard of disclosure is that considering the information that would be shared by a reasonably competent physician in comparable circumstances protects physicians' judgments about how to properly allocate time between informational disclosure and medical or surgical treatment

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[105] CA 1303/09 Kadosh v. Bikur Cholim Hosp.
[106] *Id.*
[107] *Id.*
[108] Martin R. Studer, *The Doctrine of Informed Consent: Protecting the Patients Right to Make Informed Health Care Decisions*, 48 Mont. L. Rev. 85, 85 (1987).

(although this tension is not inevitable, as information and counseling can also be provided by non-physicians).[109]

More recently, the Wisconsin Supreme Court held that physicians do not have a duty to inform patients about diagnostic tests unrelated to the condition identified in the physicians' non-negligent diagnoses.[110] In *Jandre v. Wisconsin*,[111] Thomas W. Jandre drank some coffee, which came out through his nose.[112] He began to drool, his speech became slurred, and the side of his face drooped.[113] In the emergency room, a physician diagnosed him with Bell's Palsy.[114] Eleven days later, Jandre had a full-blown stroke.[115] Jandre sued the physician for negligently diagnosing him with Bell's Palsy.[116] While a jury did not find the physician negligent, it did find that she had breached her duty under Wisconsin law by failing to inform the patient of a diagnostic test (a carotid ultrasound) that was available for ruling out the possibility of an ischemic stroke.[117] The Wisconsin Court of Appeals affirmed.[118]

On review in the Wisconsin Supreme Court, the following question was considered: Does the physician have a "duty to inform the patient about diagnostic tests for conditions unrelated to the condition" identified in the physician's non-negligent diagnosis?[119] Analyzing this question, the Wisconsin Supreme Court discussed the financial limitations of informed consent as a way of striking a balance between "allow[ing] physicians to confidently perform their

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[109] *See generally* BARRY FURROW et al., HEALTH LAW, CASES, MATERIALS AND PROBLEMS 240 (6th ed. 2008);
HALL et al., *supra* note 16, at 128.

[110] Jandre v. Wis. Injured Patients & Fams. Comp. Fund, 813 N.W.2d 627, 687 (Wis. 2012).

[111] 813 N.W. 2d 627 (Wis. 2012).

[112] *Id.* at 640.

[113] *Id.*

[114] *Id.*

[115] *Id.* at 641.

[116] *Id.* at 634.

[117] *Id.*

[118] *Id.*

[119] *Id.*

. . . work without fearing unfair and that give patients a meaningful opportunity to intelligently exercise their right of self-determination."[120] The court suggested that the reasonable approach to informed consent, namely that the physician should make those disclosures that appear reasonably necessary under the circumstances, creates such a balance.[121]

A second example involves the use of decision support tools that provide patients with specific, detailed information about options and outcomes and help them through the decision-making process, e.g., DVDs, online tools, brochures, etc.[122] The State of Washington recently revised its informed consent law to create a presumption of informed consent if a practitioner uses shared decision-making with decision aids.[123] Hence, subsection (2) of the Washington Revised Code Annotated § 7.70.060 states that

> [i]f a patient while legally competent, or his or her representative if he or she is not competent, signs an acknowledgment of shared decision making as described in this section, such acknowledgment shall constitute prima facie evidence that the patient gave his or her informed consent to the treatment administered and the patient has the burden of rebutting this by clear and convincing evidence.

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[120] *Id.* at 635–36.

[121] *Id.* at 636. For a critique on this decision, see generally Krista J. Sterken et al., *Mandatory Informed Consent Disclosures in the Diagnostic Context: Sometimes Less Is More*, 17 N.Y.U. J. LEGIS. & PUB. POL'Y 103 (2014); Michael Rohde, Comment, *Information Overload: How the Wisconsin Supreme Court Expanded the Doctrine of Informed Consent*, 46 J. MARSHALL L. REV. 1097 (2013).

[122] *See* David R. Rovner et al., *Decision Aids for Benign Prostatic Hyperplasia: Applicability Across Race and Education*, 24 MED. DECISION MAKING 359, 359 (2004); John E. Wennberg & Philip G. Peters, Jr., *Unwarranted Variations in the Quality of Health Care: Can the Law Help Medicine Provide a Remedy/Remedies?*, 37 WAKE FOREST L. REV. 925, 934–35 (2002).

[123] WASH. REV. CODE ANN. § 7.70.060 (West 2018).

The new law also allows a health care practitioner other than the physician to discuss this information with the patient.[124] The move toward shared decision making,[125] along with these specific changes, facilitate informed consent and is also intended to save physicians' time.

A third example involves federal regulations that ban any inducement by HMOs to reduce or limit services provided for Medicare or Medicaid patients under the direct care of the physician.[126] However, financial incentives that affect only physicians' time and effort, while their income, such as capitation for primary care physicians' services, are not restricted. "Also exempt from regulation are incentives that are pooled across a group of doctors who treat a large number of patients (25,000) so that withholding care from any one of them for financial reasons does not impose any substantial penalty on the responsible physician."[127] Although these rules are not the norm and still need to be adopted by states and applied to private insurers, they reflect the legislators' attitudes toward physicians' conflicts of interest arising from their financial incentives and the impact on the extent and content of information to be disclosed to patients.

A fourth example involves the recent national open payments program, known as the Physician Payment Sunshine Act.[128] The purpose of this program is to provide patients with information about the physician's financial relationship with drug and device manufacturers, group purchasing organizations (GPOs), and certain health care providers, thus allowing patients "to have more informed discussions with their doctors about the care they

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[124] *Id.*

[125] *See generally* Jaime Staples King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 AM. J.L. & MED. 429 (2006).

[126] 42 C.F.R. § 417.497 (2018).

[127] HALL ET AL., *supra* note 16, at 72.

[128] Ted Doolittle, *Increasing Transparency in Health Care with Open Payments*, CMS BLOG (Feb. 7, 2014), https://www.cms.gov/blog/increasing-transparency-health-care-open-payments.

receive."[129] Starting from 18 February 2014, some of these organizations began submitting "data to the CMS about payments made to health care providers, including gifts, consulting fees, and research activities."[130] Later, beginning in May 2014, manufacturers were required to submit additional detailed payment information.[131] Following review and correction of inaccuracies, the CMS posted the data on its website in September 2014.[132] This policy is in addition to the modification of the administration's policy on disclosure of physician payment information following recent case law[133] and public comments,[134] according to which the CMS will now evaluate requests for individual physician payment information or requests for information, which, combined with other publicly available information, could be used to determine total Medicare payments to a physician on a case-by-case basis.[135]

2. *Changes Affecting the Content of Informed Consent*

In addition to the above legal changes, there have been other recent revisions to the content of the informed consent doctrine, specifically referring to the information that should not be disclosed

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[129] *Id.*

[130] *Id.*

[131] *Id.*

[132] *Id.*; *see also* Alyce C. Katayama, *The Sunshine Act: It's for Real Now*, 112 WIS. MED. J. 96, 96 (2013).

[133] *See, e.g.,* Fla. Med. Ass'n, Inc. v. U.S. Dep't of Health, Educ. & Welfare, 601 F.2d 199 (5th Cir. 1979).

[134] Ctrs. for Medicare & Medicaid Servs., *Public Comment on the Release of Medicare Physician Data*, CMS.GOV, https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/Public-Comment.html (last modified Oct. 29, 2013, 11:56 a.m.).

[135] Modified Policy on Freedom of Information Act Disclosure of Amounts Paid to Individual Physicians Under the Medicare Program, 79 Fed. Reg. 3205, 3205 (Jan. 17, 2014); Robert Steinbrook, *Public Disclosure of Medicare Payments to Individual Physicians*, 311 J. AM. MED. ASS'N. 1285, 1285 (2014).

to the patient.[136] First, the aforementioned regulations of the contracts between HMOs and physicians and the new CMS policy hold that it is the responsibility of the HMOs or CMS, rather than the treating physician, to notify the patients about the incentive plans that may affect the use of referrals.[137] Moreover, in contrast to the common conceptualization of informed consent, under these regulations and policies, disclosure is generally required only if the patient requests it, and at the time of enrollment in a program, rather than at the time when the treatment is being offered.[138]

Moreover, in some legal decisions, including a United States Supreme Court case from 2000 in which the Court discussed cases in which physicians received financial incentives from an HMO and consequently refused to refer patients for further tests or to specialists, or delayed treatment, and as a result the patient died or suffered serious physical harm, the courts refused to acknowledge a separate claim for breach of fiduciary duty arising from the physicians' failure to disclose their financial incentive scheme with the HMO.[139] In *Pegram v. Herdrich*,[140] Cynthia Herdrich was covered by Carle HMO.[141] She was examined by a Carle physician, Lori Pegram, for pain in the midline area of her groin.[142] "Six days later, Dr. Pegram discovered a six by eight centimeter inflamed mass in Herdrich's abdomen."[143] However, "Dr. Pegram did not order an ultrasound diagnostic procedure at a local hospital, but decided that Herdrich would have to wait 8 days for an ultrasound at a facility staffed by Carle more than 50 miles away."[144] While Herdrich

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[136] *See* Wolf, *supra* note 12, at 1665–70.
[137] *Id.* at 1654 n.112.
[138] *Id.* at 1653, at 1653 nn.106–07, 1680.
[139] *Pegram*, 530 U.S. at 214.
[140] *Id.*
[141] *Id.* at 215.
[142] *Id.*
[143] *Id.*
[144] *Id.*

waited for the ultrasound, her appendix ruptured, leading to peritonitis.[145]

Herdrich sued Carle and the physician in state court for malpractice and later added two counts of state-law fraud.[146] Following the respondents' answer that the Employee Retirement Income Security Act (ERISA) preempted the new counts, the case went to federal court.[147] Herdrich amended her fraud count by alleging that the provision of medical services under Carle's terms of "rewarding its physician owners for limiting medical care entailed an inherent anticipatory breach of an ERISA fiduciary duty, since these terms created an incentive to make decisions in the physicians' self-interest" rather than those of the plan participants.[148] According to this argument, "Carle, acting though its physician owners, breached its duty to act solely in the interests of beneficiaries by making decisions affecting medical treatment while influenced by the terms of the Carle HMO scheme."[149]

"The original malpractice counts were tried by a jury and Herdrich prevailed on both, receiving $35,000 in compensation for her injury."[150] "She then appealed the dismissal of the ERISA claim

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[145] *Id.*

[146] *Id.*

[147] *Id.*

[148] Under ERISA,

> a person is a fiduciary with respect to a plan . . . [if] he [or she] exercises any discretionary authority or discretionary control . . . [for the] management of such a plan, or . . . any authority or control . . . [for the] management or disposition of its assets, . . . renders investment advice for a fee or other compensation, direct or indirect, . . . [for] any moneys or other property of such plan, . . . [or has] any discretionary authority or discretionary responsibility in the administration of such plan.

29 U.S.C. § 1002(21)(A) (2012). For a detailed analysis of fiduciary case law under ERISA, see STEVEN J. SACHER ET AL., EMPLOYEE BENEFITS LAW ch. 10, § II (2d ed. 2000).

[149] *Pegram*, 530 U.S. at 226.

[150] *Id.* at 217.

to the Court of Appeals for the Seventh Circuit, which reversed" the jury's verdict.[151] The court held that Carle was acting as a fiduciary when its physicians made the challenged decisions and "that incentives can lead to a breach when the fiduciary between plan participants and plan fiduciaries no longer exists," for example when physicians delay necessary treatment or withhold proper care for plan beneficiaries for the sole purpose of increasing their bonus.[152]

The United States Supreme Court reversed the decision, ruling that although the relationship between refusing medical treatment and physician reward was not covered under the Carle scheme, no HMO could survive without some incentive connecting physicians' rewards with treatment rationing, so that there must be some rationing and inducement to ration.[153] However, the Court held that courts are not equipped, or, at least, are less equipped than the Congress to draw the line between good and bad HMOs in terms of their rationing scheme, since doing so would involve facts to which the courts would not have access, such as correlations between malpractice rates and various HMO models, correlations involving fee-for-service models, and so on.[154] For that reason, the United States Supreme Court proceeded on the assumption that the decision in Herdrich's complaint could not be subject to a claim that Herdrich's treating physicians violated fiduciary standards unless all such decisions by all HMOs acting through their owner or employee physicians were judged by the same standards and subject to the same claims.[155]

While the fiduciary duty of a trustee is understood in common law as a duty of loyalty to guarantee the beneficiaries' interests, and specifically to display complete loyalty to the interests of the beneficiary and exclude all selfish interests and all

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[151] *Id.*

[152] Herdrich v. Pegram, 154 F.3d 362, 373 (7th Cir. 1998), *rev'd*, 530 U.S. 211 (2000).

[153] *Pegram*, 530 U.S. at 221.

[154] *Id.* at 221–22.

[155] *Id.* at 222.

consideration of the interests of third parties throughout the administration of the trust,[156] the Court held that under ERISA, a fiduciary may have financial interests adverse to beneficiaries, so that the question is not whether the action of some person providing services under a plan adversely affected a plan beneficiary's interest, but whether that person was performing a fiduciary action when performing the action that is the subject of the complaint.[157] The Court held that the specific payout details of the Carle plan were a feature that the employer, as the sponsor of the plan, was free to adopt without breach of any fiduciary duty under ERISA, since the employers' decisions about the content of the plan are not themselves fiduciary acts, and that Congress did not intend Carle or any HMO to be treated as fiduciaries to the extent that it makes a mixed eligibility decision acting through its physicians.[158] However, in footnote 8 of the decision, the Court wrote, "[a]lthough we are not presented with the issue here, it could be argued that Carle is a fiduciary insofar as it has discretionary authority to administer the plan, and so it is obligated to disclose characteristics of the plan and of those who provide services to the plan, if that information affects beneficiaries' material interests."[159] However, the Court commented that it would be acting contrary to congressional policy if it were to entertain an ERISA fiduciary claim portending wholesale attacks on existing HMOs solely because of their structure.[160] Moreover, imposing a fiduciary duty on HMO physicians would not lead to a

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[156] *Id.* at 224.

[157] *Id.* at 225–26. The *Pegram* case does not address fiduciary relationships in general or the physician-patient relationship in particular. Rather, *Pegram* focuses solely on the specific, statutorily-defined role of an ERISA fiduciary. *See generally* E. Haavi Morreim, *Another ERISA Twist: The Mysterious Case of* Pegram *and the Missing Fiduciary*, 63 U. PITT. L. REV. 235, 279 (2002); E. Haavi Morreim, *ERISA Takes a Drubbing:* Rush Prudential *and Its Implications for Health Care*, 38 TORT TRIAL & INS. PRAC. L.J. 933, 940 (2003).

[158] *Pegram*, 530 U.S. at 226, 231.

[159] *Id.* at 227 n.8.

[160] *Id.* at 234.

simple default rule, say, that whenever it is reasonably possible to disagree about treatment options, the physician should choose the more aggressive treatment.[161] Nor would it be possible to translate fiduciary duty into a standard that would allow recovery of damages from an HMO whenever a mixed decision influenced by the HMO's financial incentive resulted in a bad outcome for the patient.[162] It follows that every claim of fiduciary standard would be the malpractice standard traditionally applied in actions against physicians.[163] Therefore, the Court ruled that mixed eligibility decisions by HMO physicians are not fiduciary decisions under ERISA and reversed the Court of Appeals.[164]

However, following the Court's remark in footnote 8, and reviewing *Pegram* more generally, some legal scholars argue that *Pegram* may become the basis for expanded state authority over medical cost control.[165] In this view, *Pegram* is read as limiting lawsuits subject to ERISA preemption under federal law and, as such, allowing challenges to proceed in state courts.[166]

The issue of disclosing physicians' financial interests was raised again in a case that followed *Pegram,* in the matter of *Neade v. Portes*.[167] Anthony Neade was thirty-seven years old when he started showing symptoms of coronary artery blockage.[168] In addition to his physical symptoms, he had a family history of heart disease, was overweight, suffered from hypertension, and smoked,

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[161] *Id.*

[162] *Id.*

[163] *Id.* at 235.

[164] *Id.* at 237.

[165] *See, e.g.,* Timothy S. Jost, Pegram v . Herdrich*: The Supreme Court Confronts Managed Care*, 1 Yale J. Health Pol'y L. & Ethics 187, 190 (2001).

[166] *See* Pappas v. Asbel, 768 A.2d 1089, 1095 (Pa. 2001); PETER D. JACOBSON, STRANGERS IN THE NIGHT: LAW AND MEDICINE IN THE MANAGED CARE ERA 165–66 (2002); Jost, *supra* note 165, at 187); *see also* MANAGED CARE LITIGATION 193–94 (Julie A. Barnes et al. eds., 2005). *But see* Corp. Health Ins., Inc. v. Texas Dep't of Ins., 215 F.3d 526, 540 (5th Cir. 2000).

[167] Neade v. Portes, 710 N.E.2d 418 (Ill. App. Ct. 1999), *aff'd in part, rev'd in part*, 739 N.E.2d 496 (Ill. 2000).

[168] *Id.* at 421.

and he had a high cholesterol count.[169] Neade was hospitalized but discharged after three days.[170] He kept complaining of stabbing chest pain.[171] His primary care physician, Dr. Portes asked his associate, Dr. Huang, to examine Neade.[172] Dr. Huang recommended that Neade undergo an angiogram, a more specific test for artery disease than the one Neade underwent at the hospital.[173] Without examining Neade, Dr. Portes refused to authorize Neade's hospitalization for an angiogram.[174] About eight months later, Neade returned to Dr. Portes complaining of chest pain radiating up the right side of his neck, as well as sweating.[175] Another part-time employee of the medical center, Dr. Schlager, examined Neade and also recommended an angiogram.[176] However, Dr. Porter again refused to authorize hospitalization without examining Neade, relying on the previous tests he had undergone at the hospital.[177] Three months later Neade suffered a massive myocardial infarction caused by coronary artery blockage and died nine days later.[178]

The case reveals that, as president of the medical center (Primary Care Family Center), Dr. Portes negotiated and entered into contracts with various entities, including the Chicago HMO, which covered Neade's health insurance.[179] The contract provided a capitation fee for subscribers of the Chicago HMO who utilized

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[169] *Id.*
[170] *Id.*
[171] *Id.*
[172] *Id.*
[173] *Id.*
[174] *Id.*
[175] *Id.*
[176] *Id.*
[177] *Id.*
[178] *Id.*
[179] *Id.*

services of Primary Care, including referrals for tests.[180] According to this contract, any monies left in the Medical Incentive Fund at the end of the twelve months contract period would be split 60-40 between Primary Care and the Chicago HMO.[181] Therefore, if Neade received an angiogram and a referral to a specialist, those fees would be paid from the Medical Incentive Fund administrated by Primary Care.[182]

The plaintiff alleged that Dr. Portes had breached his fiduciary duty to Neade not only by refusing to authorize further testing for him, but also by failing to disclose Primary Care's financial relationship with Chicago HMO, including the Medical Incentive Fund.[183] In the plaintiff's allegation, the contract with Chicago HMO put the financial well-being of Primary Care in direct conflict with Neade's physical well-being.[184] The state appellate court referred to previous federal case law establishing a patient's cause of action against an HMO in a breach of fiduciary duty for failing to disclose its financial incentive scheme with its physicians.[185] In cases such as these, which involved the treating physician's refusal to refer the patient to a specialist[186] or delaying an ultrasound at a plan hospital located 50 miles away,[187] the patients relied on their doctor's advice about treatment options and needed to know whether "the advice [was] influenced by self-

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[180] *Id.*

[181] *Id.*

[182] *Id.*

[183] *Id.*

[184] *Id.*

[185] *Id.*; *Herdrich*, 154 F.3d at 380 ("The language of the plaintiff's complaint is sufficient in alleging that the defendants' incentive system depleted plan resources so as to benefit physicians who, coincidentally, administered the Plan, possibly to the detriment of their patients."); Shea v. Esensten, 107 F.3d 625, 629 (8th Cir. 1997) ("When an HMO's financial incentives discourage a treating doctor from providing essential health care referrals for conditions covered under the plan benefit structure, the incentives must be disclosed and the failure to do so is a breach of ERISA's fiduciary's duties."). The *Herdrich* case was reversed by the United States Supreme Court, which held that the decisions about how to diagnose or treat a patient's condition, and whether the patient's medical plan covered the condition or its treatment, "made by an HMO acting through its physicians, were not fiduciary acts within the meaning of ERISA." *Pegram*, 530 U.S. at 211, 214.

[186] *Shea*, 107 F.3d at 627.

[187] *Herdrich*, 154 F.3d at 374.

serving financial considerations created by the health insurance provider."[188]

In reviewing case law about the fiduciary duty of physicians towards their patients, the court held that while many jurisdictions hold that a physician has a fiduciary relationship with his patient, there is no consensus as to whether a patient can bring an action against his or her physicians for breach of fiduciary duty.[189] Thus, while in *Moore v. Regents of the University of California*, the Supreme Court of California held that a physician must disclose personal interests, whether research or economic, unrelated to the patient's health that may affect the physician's professional judgment, and that failure to do so may give rise to a cause of action for breach of fiduciary duty or for performing medical procedures without informed consent,[190] in *D.A.B. v. Brown*,[191] the Minnesota appellate court refused to acknowledge a separate claim for breach of fiduciary duty arising from a physician's failure to disclose a scheme whereby the distributor of a drug had paid the physician to induce him to prescribe that drug to patients, and so did other courts in other jurisdictions.[192] Yet, in those cases, the breach of fiduciary duty also constituted a medical negligence claim.[193] Hence, for example, the court in *Brown* held that "any breach of fiduciary duty

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[188] *Shea,* 107 F.3d at 628.

[189] *Id.* at 629.

[190] Moore v. Regents of Univ. of Cal., 793 P.2d 479 (Cal. 1990). In this case, the physician had an interest in developing biotechnology products out of cells taken from the patient's diseased spleen. *Id.* at 482. The court held that this should have been disclosed prior to surgery and post-surgical care. *Id.* at 485. It was ruled that "a reasonable patient would want to know whether a physician has an economic interest that might affect the physician's professional judgment." *Id.* at 483 However, one can argue that *Moore* is different than *Pegram* and cases alike in that in *Moore*, the physician did not disclose his own gains and the property that the patient may have had, whereas in the other cases the physician had an incentive not to disclose something involving the patient's healthcare choices.

[191] 570 N.W.2d 168 (Minn. App. 1997).

[192] *Id.* at 172–73.

[193] *Id.* at 172.

that may have occurred during the doctor's prescription of medication to his patients arose while the doctor was examining, diagnosing, treating, or caring for his patients" and thus constituted a claim of medical negligence.[194]

In *Neade*, the court held that in some instances the plaintiff may be able to plead a cause of action for breach of fiduciary duty separate from medical negligence.[195] The court based its decision on Illinois legislation, such as the Health Care Worker Self-Referral Act 225 ILCS 47/20(b)(7), which "prohibits a health care worker from referring a patient for health services to an entity in which he is an investor and for which he does not provide direct services, unless he discloses his interest to the patient"; section 8.132 of the opinions of the Council on Ethical and Judicial Affairs of the American Medical Association (1996–1997), which prohibits physicians from denying their patients access to appropriate medical services based on personal financial reward or the avoidance of financial penalties and imposes a duty to disclose any financial inducements that may tend to limit the diagnostic and therapeutic alternatives that are offered to patients or may tend to limit patients' access to care; and an analogy from case law that recognizes a separate cause of action for breach of fiduciary duty that a client can bring against his attorney.[196]

However, on appeal, the Illinois Supreme Court reversed the decision and refused to acknowledge a fiduciary duty of physicians to disclose financial incentives that may have led them to deny treatment in specific case.[197] In addition to finding that the plaintiff's breach of fiduciary duty claim was a re-presentment of her medical negligence claim, the court held that the legislation in Illinois,

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[194] *Id.* Moreover, the court was concerned that a plea for breach of fiduciary duty might be made to avoid statutes of limitations and the requirement of proving actual injury in a medical malpractice claim. *Id.* at 171.

[195] *Neade*, 710 N.E.2d at 427.

[196] *Id.* at 426.

[197] Neade v. Portes, 739 N.E.2d 496, 506 (Ill. 2000).

specifically the Managed Care Reform and Patients Rights Act, had chosen to put the burden of disclosure of any financial incentive plan on the HMO rather than the physician.[198] The court further ruled that the effects of acknowledging such a duty and recognizing its breach in an era when physicians treat numerous patients—many of whom are covered by different HMOs—would be unworkable.[199] This is because "in order to effectively disclose HMO incentives, physicians would have to remain cognizant at all times of every patient's particular HMO and that HMO's policies and procedures."[200] The court concluded that while it agreed that patients should be told of "financial considerations which may negatively impact their health care, it would not place the burden of that disclosure on physicians."[201]

However, a dissent by Chief Justice Harrison stated that, as with lawyers and their clients, doctors not only owe their patients a duty of care, but also a fiduciary duty.[202] In the case before him, Justice Harrison explained that Dr. Portes's failure to disclose that he had a financial incentive for denying the test recommended by his two associates, and which the patient needed, "trigger . . . separate policy considerations and constitutes an independent wrong."[203] Referring to American Medical Association (AMA) guidelines endorsed by the lower court, and the Health Care Worker Self-Referral Act, which imposes stringent conditions upon when a physician or other health worker may refer a patient to another office or group practice in which the physician or the worker is an investor, Justice Harrison further explained that there was nothing in the

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[198] *Id.* at 503–04.
[199] *Id.* at 504.
[200] *Id.*
[201] *Id.* at 505.
[202] *Id.* at 506 (Harrison, J., dissenting).
[203] *Id.* at 507 (Harrison, J., dissenting).

Managed Care Reform and Patient Rights Act, on which the majority supported its decision, to suggest that an HMO's duty to disclose the financial relationships between the health care plan and its health care providers "supplants or supersedes the independent legal and ethical duty of a physician to divulge his financial interests in withholding care from a patient."[204] In his view, interpreting "the Act as excusing physicians from their own disclosure obligations would diminish patients' access to information and undermine the purpose of the law."[205]

Importantly, Justice Harrison discussed that allowing "health plan participants to make written requests for disclosure of the financial relationship between the plan and its providers" is valuable for a patient who is selecting a health plans and care providers.[206] "It is of less benefit when a patient is already in a plan, under the care of a provider and facing treatment choices."[207] "If there is any possibility that the course of treatment recommended by the provider may be affected by the plan, the patient has a right to know about it and the care provider has an obligation to disclose it."[208]

Justice Harrison also stated that the physician's duty to disclose this information should not depend on a specific request from the patient, especially not a written request.[209] In his view, "most people trust their doctors and would never imagine that their own physician might be withholding necessary medical care for personal, financial reasons."[210] Rejecting the majority view that

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[204] *Id.* (Harrison, J., dissenting).

[205] *Id.* (Harrison, J., dissenting). Compare this ruling with legal rules suggesting that the legal responsibility for informed consent is the physician's and not the hospital's, and that the hospital only assists in administrating the process. *See generally* Gotlin v. Ledermann, 367 F. Supp. 2d 349 (E.D.N.Y. 2005); Foster v. Traul, 120 P.3d 278 (Idaho 2005).

[206] *Neade*, 739 N.E.2d at 507 (Harrison, J., dissenting).

[207] *Id.* at 508 (Harrison, J., dissenting).

[208] *Id* (Harrison, J., dissenting)..

[209] *Id.* (Harrison, J., dissenting).

[210] *Id.* (Harrison, J., dissenting).

such a duty of disclosure would be burdensome, Justice Harrison stated that there was no reason why physicians cannot "manage or afford the administrative tools to keep them fully apprised of the payment incentives affecting a particular patient's care."[211] In his view, the plaintiff could proceed with a claim of breach of fiduciary duty along with her claim for negligence.[212]

Finally, another example of the legal change in the content of informed consent involves the recent rules under section 3022 of the Patient Protection and Affordable Care Act regarding the new ACO system.[213] According to these regulations, "ACO participants must notify beneficiaries at the point of care that their ACO provider/suppliers are participating" in the MSSP applying to Medicare beneficiaries.[214] ACO participants must also post signs in their facilities to notify beneficiaries that their provider/suppliers are participating in that program.[215] The justification for this beneficiary notice is that the beneficiary can choose not to be aligned with an ACO, and later on opt out of data sharing permitted under the MSSP.[216] Moreover, because "beneficiaries [may be] misled about Medicare services available from an ACO and about the choice of their providers," the CMS's final rule provides a template for such a message and holds that all initial and revised ACO marketing materials and activities must be submitted to CMS before use.[217]

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[211] *Id.* (Harrison, J., dissenting).

[212] *Id.* (Harrison, J., dissenting).

[213] Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3022, 124 Stat. 395 (2010).

[214] 42 C.F.R. § 425.312(a)(1) (2018).

[215] *Id.*; 42 C.F.R. § 425.312(a) (2005); *see generally* Ctrs. for Medicare & Medicaid Servs., *supra* note 73. For an excellent and detailed discussion of this program, see THE ACO HANDBOOK: A GUIDE TO ACCOUNTABLE CARE ORGANIZATIONS (Peter A. Pavarini et al. eds., 2d ed. 2015).

[216] Danielle L. Trostorff, *Certification and Licensure*, in THE ACO HANDBOOK, *supra* note 215, at 202–03.

[217] *Id.* at 208; *see also* 42 C.F.R. § 425.310.

Justice Harrison's reasoning in *Neade*, the new federal regulations imposing a duty of disclosure in the ACO scheme, the Sunshine Act, and the revised CMS policy on disclosure of physician payment information, all suggest a legal change in the area of physician disclosure that will lead to a dramatic shift in the way physicians and patients behave. Regardless of the question of whether the new ACO delivery system is different from or similar to managed care,[218] and its ethical implications,[219] these legal rules suggest that the scope of disclosure should be broadened to meet the recent changes in the health system. In contrast, reviewing the other types of legal changes to the doctrine of informed consent, i.e., those applying to the setting in which the duty to disclose material information to patients is carried out, reveals a shift in the opposite direction, namely narrowing the extent to which and limiting the time at which disclosure is to be made. As argued, such changes are prompted as a result of organizational, time, and economic limits put on health providers. In addition to this puzzling finding, one should also consider other legal rules discussing the economizing role of physicians and their rationing and gate-keeping functions and those considering disclosure of information pertaining to physicians' personal characteristics.

3. *Other Relevant Legal Changes in the Doctrine of Informed Consent*

Courts have generally refused to find a hospital or physician liable for failing to advise their patients that they were eligible for government funding, e.g., Medicaid.[220] Nor is a physician liable for the financial consequences of a misdiagnosis when, for example, a patient canceled a life insurance policy upon being erroneously

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[218] *See, e.g.*, Ezekiel J. Emanuel, *Why Accountable Care Organizations Are Not 1990s Managed Care Redux*, 307 J. AM. MED. ASS'N 2263, 2263–64 (2012).

[219] Daniel Sperling, *(Re)Disclosing Physician Financial Interests: Rebuilding Trust or Making Unreasonable Burdens on Physicians?*, 20 MED. HEALTH CARE & PHIL. 179, 182–84 (2017).

[220] *See, e.g.*, Mraz v. Taft, 619 N.E.2d 483 (Ohio Ct. App. 1993).

diagnosed as not having cancer.[221] Likewise, the California Supreme Court ruled, in a leading decision, that physicians, despite their fiduciary status, are not bound to disclose a cancer patient's short life expectancy so that he can put his financial and business affairs in order.[222] The court held that informed consent does not require disclosure of risks involving nonmedical interests, nor everything a patient might want to know.[223]

While the courts have been unanimous in determining that the treating physician is not the patient's financial advisor and need not discuss the patient's financial or other non-medical interests, some courts have recently expanded the duty of disclosure to any provider-specific information, including the physician's experience and skill,[224] the physician's health status,[225] the physician's addictions,[226] the physician's research interests,[227]etc.[228] The courts have regarded the physician's lack of experience in some cases as a material risk to be disclosed to the patient. For example, in *Goldberg v. Boone,* the Maryland appellate court broadly defined a material risk as one that a physician knows or should have known would be important to a reasonable person in the patient's position in deciding whether or not to submit to a particular medical treatment or

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[221] In re Est. of Blacher, 857 P.2d 566, 568 (Colo. Ct. App. 1993).

[222] Arato v. Avedon, 858 P.2d 598 (Cal. 1993).

[223] *Id.* at 600.

[224] *See, e.g.*, Willis v. Bender, 596 F.3d 1244 (10th Cir. 2010); Housel v. James, 172 P.3d 712 (Wash. Ct. App. 2007); Johnson by Adler v. Kokemoor, 545 N.W.2d 495 (Wis. 1996); *see also* Steve Clarke & Justin Oakley, *Informed Consent and Surgeons' Performance*, 29 J. MED. & PHIL. 11 (2004); Richard J. Veerapen, *Informed Consent: Physician Inexperience Is a Material Risk for Patients*, 35 J.L. MED. & ETHICS 478 (2007); *but see* Howard v. Univ. of Med. & Dentistry of N.J., 800 A.2d 73 (N.J. 2002); HALL ET AL., *supra* note 20, at 134.

[225] Est. of Behringer v. Med. Ctr. at Princeton, 592 A.2d 1251, 1283 (N.J. Super. Ct. 1991).

[226] Schwaller v. Maguire, No. C-020555, 2003 WL 22976339, at ¶19–22 (Ohio Ct. App. Dec. 19, 2003).

[227] *Moore*, 793 P.2d at 484–86.

[228] *But see generally* Albany Urology Clinic v. Cleveland, 528 S.E.2d 777 (Ga. 2000) (acknowledging no duty to disclose substance abuse).

procedure.[229] Under this broad definition of "material risk," the physician's financial interests that affect his or her medical decision-making can also be included.

V. SCHOLARLY SUGGESTIONS FOR RE-CONCEPTUALIZING THE REQUIREMENT OF INFORMED CONSENT

Along with these changes in case law and legislation, other revisions to the doctrine of informed consent have been recommended by some scholars, specifically, legal revisions. Mark Hall, for example, argued that physicians practicing with constrained resources often unconsciously engage in implicit rationing, and disclosing the physician's trade-offs would undermine the patient's trust.[230] It follows that patient's prior consent to a rationing scheme should relieve the physician of the duty to disclose treatments that he or she is withholding due to the costs.[231] The waiver of the physician's duty to disclose non-treatment decisions also stems from what Hall terms "silent rationing."[232] In this view, subscription to a health plan is seen as a waiver of the right to be informed about spending decisions.[233] The concept of prior consent and the waiver of informed consent constitute what Hall calls the "theory of economic informed consent."[234] In the wake of this suggestion, other scholars argue that the doctrine of informed consent should be subject to cost-benefit analysis and modified,[235] and that the doctrine of informed consent calls for a shift from a stakeholder theory in bioethics to a new domain—that of organizational ethics.[236]

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[229] Goldberg v. Boone, 912 A.2d 698, 702 (Md. 2006).

[230] HALL, *supra* note 33, at 205.

[231] *Id.* at 204–05.

[232] Mark A. Hall, *A Theory of Economic Informed Consent*, 31 GA. L. REV. 511, 512, 566 (1997).

[233] *Id.*

[234] *Id.* at 512.

[235] Peter H. Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 904–05 (1994); Wolf, *supra* note 12, at 1636–38.

[236] Wolf, *supra* note 12, at 1647–48.

Paul Menzel went on to argue that health plan subscribers are presumed to have given consent at the point of treatment, when it is clear that the patients would have consented at subscription.[237] Since rationing is viewed differently on these two occasions, Menzel prefers to accept the more dispassionate choices the patient would have made at the earlier point.[238] However, at the time of treatment, the physician has a duty to disclose the information only if it could realistically lead—in the opinion of the physician—to making other decisions, including purchasing the care out of pocket or switching to a plan with a different rationing system.[239]

In line with Hall's and Menzel's theories, Clark Havighurst and Gregg Bloche argued that patients choose in advance to economize on care by signing insurance contracts that authorize health plans to set limits.[240] By accepting these limits, physicians are respecting their patients' autonomy because the patients accepted these limits when they signed up for coverage.[241] In Havinghurst and Bloche's view, the major effect of changes in the financing and organization of health services has been to shift the focus of consent from the time of treatment to the moment when people sign up for health plans.[242] According to this argument, physicians are not in a conflict of interests when they set limits on behalf of the health plans.[243] On the contrary, they are honoring their patients' preferences and affirming their freedom to enter into contracts.[244]

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[237] PAUL T. MENZEL, STRONG MEDICINE: THE ETHICAL RATIONING OF HEALTH CARE 13 (1990).

[238] *Id.*

[239] *Id.* at 145.

[240] M. GREGG BLOCHE, THE HIPPOCRATIC MYTH: WHY DOCTORS AARE UNDER PRESSURE TO RATION CARE, PRACTICE POLITICS, AND COMPROMISE THEIR PROMISE TO HEAL 104 (2011).

[241] *Id.*

[242] *Id.* at 104–05.

[243] *Id.* at 105.

[244] *Id.*

Although some of these theoretical suggestions have been criticized,[245] they purport to correct, and thus call into question, bioethics' excessive enthusiasm for patient autonomy.[246] The recommended revisions of the requirement of informed consent, along with the new limits on it set by recent case law and legislation, seriously challenge the law's contribution to the idea of informed consent and its traditional role in offering a better standard of care, reform, and the promotion of the patient's best interests in comparison to what could be secured by medical ethics alone.

VII. PRIMA FACIE ETHICAL EVALUATION OF THE LEGAL CHANGES IN THE DOCTRINE OF INFORMED CONSENT

In its code of medical ethics, the American Medical Association (AMA) specifically addresses the issue of physicians' disclosure of the limitations of their treatment resulting from self-interest. Thus the AMA's Opinion 8.132 stipulates,

> Physicians should always make referral decisions based on *the best interests of their patients*, regardless of the financing and delivery mechanisms or contractual agreements between patients, health care practitioners and institutions, and third party payers.
>
> Physicians must *ensure disclosure of any financial incentives* that may limit appropriate diagnostic and therapeutic alternatives that are offered to patients or that may limit patients' overall access to care.[247]

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[245] *See, e.g.*, Wolf, *supra* note 12, at 1666–75.

[246] HALL ET AL., *supra* note 16, at 209–11.

[247] AMA Council on Ethical & Judicial Affairs, *AMA Code of Medical Ethics' Opinions on the Physician as Businessperson*, AMA Journal of Ethics, https://journalofethics.ama-assn.org/article/ama-code-medical-ethics-opinions-physician-businessperson/2013-02 (Feb. 2013); *see also* Gen. Med. Council, *Financial and Commercial Agreements and Conflicts of Interests*, GMC-

Regardless of whether the concept of informed consent indeed developed in a model in which the patient and the individual doctor were operating largely without systemic cost constraints,[248] and whether the old version of the concept also ignored the problem of access to health services and health providers,[249] one could argue that the recent legal changes in the doctrine of informed consent resulting from the organizational and financial transformations of the health system are ethically disturbing, and although they should not necessarily be controlled by the explicit opinion of the AMA code of medical ethics, they are in sharp contradiction with it.[250]

While the doctrine of informed consent has been criticized for its failure to achieve the major goal of medicine, namely to maximize patients' best interests,[251] and has been empirically shown to be unworkable and underestimated by both physicians and patients,[252] it nonetheless purports to further important goals in medical care and human interactions in general.

UK.ORG, http://www.gmc-uk.org/guidance/ethical_guidance/30191.asp (Apr. 22, 2013) (providing the UK guidelines demanding similar requirements of doctors).

[248] Hall, *supra* note 232, at 513.

[249] Susan M. Wolf, *Health Care Reform and the Future of Physician Ethics*, 24 HASTINGS CTR. REP., Mar.–Apr. 1994, at 28, 31–32.

[250] It should be stated that the argument raised in this Article does not rely on the assumption that managed care, ACOs or privatization of health care are morally wrong. For the morality of this new development and its implications for patients' well-being and society in general, see Edmund D. Pellegrino, *Managed Care at the Bedside: How Do We Look in the Moral Mirror?*, 7 KENNEDY INST. ETHICS J. 321 (1997), and Barbara Rylko-Bauer & Paul Farmer, *Managed Care or Managed Inequality? A Call for Critiques of Market-Based Medicine*, 16 MED. ANTHROPOLOGY Q. 476 (2002).

[251] Robert M. Veatch, *Abandoning Informed Consent*, 25 HASTINGS CTR. REP., Mar.–Apr. 1995, at 5, 6–7.

[252] *See generally* Clarence H. Braddock III et al., *Informed Decision Making in Outpatient Practice: Time to Get Back to Basics*, 282 J. AM. MED. ASS'N. 2313 (1999); Wendy Levinson et al., *Not All Patients Want to Participate in Decision Making*, 20 J. GEN. INTERNAL MED. 531 (2005); Charles W. Lidz et al., *Barriers to Informed Consent*, 99 ANNALS INTERNAL MED. 539 (1983); Alan Meisel & Mark Kuczewski, *Legal and Ethical Myths About Informed Consent*, 156 ARCHIVES INTERNAL MED. 2521 (1996).

On the other hand, disclosure of physicians' financial interests may invade clinicians' privacy[253] and lead to violation of the integrity of the data and misuse of the information. By over-emphasizing one aspect of physicians' interests, disclosure may also lead to false impression that physicians are solely and exclusively motivated by monetary issues and self-interest, thereby damaging the therapeutic relationship. Over-emphasizing physicians' interest can also stigmatize physicians who maintain collaborative relationships with the industry.[254]

However, limiting the duty to disclose information to the patient due to organizational factors not only defeats the non-consequentialist rationales for informed consent, mainly respect for patients' autonomy and privacy,[255] but also makes the physician-patient relationship more asymmetrical by increasing patients' dependence on their caregivers and the organization within which they operate. Limiting the duty to disclose information exacerbates the problem of asymmetric information affecting patients and purchasers of health services, thereby making provision of health insurance and medical services less competitive.[256] Capitation payment, adherence to the economic goals of ACOs or the rationing functions of public hospitals treating a large number of patients in social health systems create serious conflicts of interest between the patient's best therapeutic interests and the physician's financial incentives (or those of the organization with which he or she has contractual relations). As a result, physicians may fail to fulfill their fiduciary duties to be honest and may compromise care due to costs or time limitations. Such an outcome may undermine the trust that is so essential to the physician-patient relationship,[257] and may also lead to abuse in some cases.

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[253] *See, e.g.,* Fla. Med. Ass'n, Inc. v. Dep't of Health, Educ. & Welfare, 479 F. Supp. 1291 (M.D. Fla. 1979), *vacated*, 947 F. Supp. 2d 1325 (M.D. Fla. 2013).

[254] *See* Sperling, *supra* note 219, at 182–83.

[255] Pellegrino, *supra* note 250, at 324.

[256] William M. Sage, *Regulating Through Information: Disclosure Laws and American Health Care*, 99 COLUM. L. REV. 1701, 1710–11 (1999).

[257] *See* Margaret McCartney et al., *Letter: Why the GMC Should Set Up A Central Registry of Doctors' Competing Interests*, 348 BRIT. MED. J. 236 (2014).

Disclosure of physician payment data may be beneficial to numerous parties. "Patients may gain broader, more reliable measures of provider quality and performance that will result in innovation and competition while informing patients' choice; health care providers may collaborate on improved care management and the delivery of health care at lower costs; and journalists and others may discover waste, fraud, abuse and unsafe practices and bring them to public attention."[258]

Given that most patients would rather not have to make many of their treatment decisions, because they may not feel competent to weigh their choice properly, or may have other reasons for trusting physicians to act in accordance with what their fiduciary agent says,[259] the fiduciary nature of the relationship is very important. As Bloche argues, "[T]he physician who takes money for *not* pursuing pricey options leaves her patients with the bitter taste of betrayal—if they found out. . . . Betrayal . . . is unnecessary, and it's toxic to the doctor-patient relationship."[260]

Moreover, by offering less than optimum information to patients, as currently guaranteed by the law, physicians working under the legal rules discussed above increase the chance that patients will not receive the best medical treatment for their condition and at times even directly harm their patients and expose

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[258] Sperling, *supra* note 219, at 182. On the effectiveness of disclosure for revealing fraud, see United States Department of Health and Human Services, *Reviews of Clinicians Associated with High Cumulative Payments Could Improve Medicare Program Integrity Efforts (A-01-11-00511)* (Dec. 2013), *available at* https://oig.hhs.gov/oas/reports/region1/11100511.pdf.

[259] CARL SCHNEIDER, THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS AND MEDICAL DECISIONS 35–46 (1998).

[260] BLOCHE, *supra* note 245, at 108 (emphasis in original). However, Bloche is trying to distinguish between "performance standards tied to trade-offs accepted by plan members and rewards to doctors for withholding care regardless of health consequences." *Id.* In his view, while "[t]he former encourage doctors to stick to the deal their patients struck[,] . . . [t]he latter incite disloyalty and arouse public ire." *Id.* at 109.

them to possible exploitation and subversion.[261] This problem is intensified when patients lack what James Childress called "second-order autonomy," namely when patients do not have freedom to choose their health plan or the health providers who are making medical decisions on their behalf.[262]

This prima facie ethical analysis should also include consideration of accumulating empirical evidence in the area of disclosure of physicians' financial interests. Data indicates that, on the one hand, patients have various complex barriers to considering costs when deciding on clinical options, as they have little interest in costs borne by insurers and society as a whole,[263] and they rarely ask directly about their physician's conflicts of interest.[264] On the other hand, most physicians avoid telling their patients how they are paid or what incentives they may have for making clinical decisions, because they believe that their patients will trust them under any circumstances,[265] and they have difficulty with rationing and with their role as gatekeepers in general.[266]

These data suggest that even though disclosure of physicians' financial interests may be the ethical choice,[267] it may not necessarily be required by patients or feasible for physicians, and in many cases, it may "significantly increase the probability that

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[261] Of course, there may be times where better patient outcomes result from physicians providing less than the optimum amount of information to their patients and even deceiving them. However, it can be argued that these are exceptional cases.

[262] JAMES F. CHILDRESS, WHO SHOULD DECIDE? PATERNALISM IN HEALTH CARE 59 (1982).

[263] Roseanna Sommers et al., *Focus Groups Highlight That Many Patients Object to Clinicians' Focusing on Cost*, 32 HEALTH AFF. 338, 343 (2013).

[264] Rita Gorawara-Bhat et al., *Patient-Provider Discussions About Conflicts of Interest in Managed Care: Physicians' Perceptions'*, 9 AM. J. MANAGED CARE 564, 567 (2003).

[265] Steven D. Pearson & Tracey Hyams, *Talking About Money: How Primary Care Physicians Respond to a Patient's Question About Financial Incentives'*, 17 J. GEN. INTERNAL MED. 75, 76–77 (2002).

[266] *See generally* Benedicte Carlsen & Ole Frithjof Norheim, "*Saying No Is No Easy Matter": A Qualitative Study of Competing Concerns in Rationing Decisions in General Practice*, 5 BMC HEALTH SERVICES RES. 70 (2005), *available at* https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-5-70.

[267] E. Haavi Morreim, *Taking a Lesson from the Lawyers: Defining and Addressing Conflict of Interest*, 11 AM. J. BIOETHICS 33, 34 (2011).

patients would reject the physician's recommendations."[268] Indeed, even if precise and complete information is disclosed, it may still be misunderstood by patients,[269] who, like other consumers, lack what William Sage calls "baseline information" to provide context for the required disclosure.[270] While pilot disclosure programs already exist,[271] and some of them have been found to increase patient loyalty,[272] some serious practical questions arise: What is the extent of the required disclosure? Should disclosure be made at the time of subscription to a health plan or at the time of treatment? Who should make the disclosure and how? Should disclosure be initiated by the physician or should it only follow a patient's request? How will public authorities monitor physicians' compliance? Should there be sanctions for failure to disclose? If so, what sanctions are appropriate and when should they apply?[273] In addition, it is important to consider the alternatives to disclosure. If disclosure of physicians' financial interests becomes mandatory or is required by ethical codes, will patients have real alternatives to choose other care providers or treatments that do not have such incentives or financial environments? Will they be able to choose among them easily and with no further cost? Indeed, some scholars do not find disclosure sufficient to fully and meaningfully inform patients about

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[268] Roy Spece et al., *An Empirical Method for Materiality: Would Conflict of Interest Disclosures Change Patient Decisions?*, 40 AM. J.L. & MED. 253, 270 (2014).

[269] Carl E. Schneider, *After Autonomy*, 41 WAKE FOREST L. REV. 411, 430 (2006); Carl E. Schneider & Mark A. Hall, *The Patient Life: Can Consumers Direct Health Care?*, 35 AM. J.L. & MED. 7, 41 (2009).

[270] William M. Sage, *Accountability Through Information: What the Health Care Industry Can Learn from Securities Regulation*, THE MILBANK MEMORIAL FUND, Nov. 21, 2000, at 1, 15, https://www.milbank.org/wp-content/uploads/2016/06/Accountability-through-Information.pdf.

[271] McCartney et al., *supra* note 256, at 2; Leana Wen, *Patients Can't Trust Doctors' Advice if We Hide Our Financial Connections with Drug Companies*, 348 BRIT. MED. J. 26 (2014).

[272] Steven D. Pearson et al., *A Trial of Disclosing Physicians' Financial Incentives to Patients*, 166 ARCHIVES INTERNAL MED. 623, 626–27 (2006).

[273] *See generally* MARC A. RODWIN, CONFLICTS OF INTEREST AND THE FUTURE OF MEDICINE: THE UNITED STATES, FRANCE, AND JAPAN 215–19 (2013); Marc A. Rodwin, *Physicians' Conflicts of Interest: The Limitations of Disclosure*, 321 NEW ENG. J. MED. 1405 (1989).

their physician's financial interests and/or prevent physicians from reducing their standard of care.[274] All of these questions are difficult and need to be addressed for a full ethical analysis of the recent changes in the doctrine of informed consent discussed here.

What is worse is that the bioethical literature has shown very little interest in the important changes in the doctrine of informed consent. Reviewing the literature[275] reveals that there are hardly any articles or books discussing these fundamental changes or endorsing the scholarly suggestions in this respect. In light of the above prima facie ethical analysis, this is a surprising phenomenon. The following part suggests some of the reasons for it. These are divided into reasons involving changes in the managed care system; those involving the relationship between ethics and law; and those that concern the characteristics of the bioethical literature.

VIII. WHY IS THERE SO LITTLE INTEREST IN THE LEGAL CHANGES IN THE DOCTRINE OF INFORMED CONSENT?

A. Managed Care Backlash

Perhaps the most intuitive and straightforward response to the question of why the bioethical literature shows so little interest in the legal changes in the doctrine of informed consent involves the managed care backlash. While managed care has been successful in controlling costs,[276] it led to a serious crisis and physicians' and

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[274] E. HAAVI MORREIM, HOLDING HEALTH CARE ACCOUNTABLE: LAW AND THE NEW MEDICAL MARKETPLACE 23–24 (2001); RODWIN, *supra* note 273, at 215–19.

[275] Although the term "literature" is used very broadly to encompass almost any kind of scholarly writing, I am using it here to refer to the most accepted journals and books in the area of bioethics, with an emphasis on ethical discussions that can be found in academic searches through such resources as the Philosopher's Index, Pubmed, and Google Scholar. I am excluding articles, book chapters, or books discussing mainly legal aspects of disclosure and/or those involving mostly descriptive analyses about the disclosure of physicians' financial interests.

[276] From 1993 to 1998, health care costs increased by 31%, a rate slower than that during any period over the last 40 years. As employers moved away from it, health care costs more than doubled from 1999 to 2010, increasing by 102%. Emanuel, *supra* note 218, at 2263.

patients' dissatisfaction, resulting in a backlash. Patients reported increased dissatisfaction with managed care, partly because of bureaucratic delays and uncertainty about whether care would be provided, and partly because decision-making was not transparent.[277] Physicians started rejecting capitation payment arrangements and gained back some bargaining power from managed care organizations.[278] Physicians complained about the organizations' antagonism toward their clinical choices and professional autonomy, and for being evaluated by non-physician managed care administrators.[279] Legal scholars and judges also criticized managed care organizations and voiced their misgivings about the cost-containment programs, their harsh results, and their lack of flexibility.[280]

In response to public demand, managed care organizations began to use more point-of-service plans that allowed patients to see out-of-network providers, and reduced their opposition to direct patient access to specialty care.[281] This was followed by state legislation restricting managed care organizations' review of clinical recommendations.[282] Such legislation includes prohibiting gag clauses and comprehensive reforms designed to limit the primacy of cost-containment.[283] As a result, new forms of health care provision were initiated. The use of consumer-driven health plans made up of a high-deductible health plan and a health savings

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[277] JACOBSON, *supra* note 161, at 154.

[278] Cara S. Lesser & Paul B. Ginsburg, *Update on the Nation's Health Care System: 1997–1999*, 19 HEALTH AFFAIRS 206, 212 (2000).

[279] *Id.*

[280] JACOBSON, *supra* note 166, at 154–55. However, as Jacobson argues, the courts have not necessarily acted on their misgivings to rule against the organizations' legal immunity. *Id.*

[281] *Id.* at 153.

[282] *Id.* at 156.

[283] *Id.* However, some courts have ruled that state legislation in this respect preempts the federal ERISA legislation that provides legal immunity for managed care. *Id.*

account have grown significantly in the past few years, since the passage of the Medicare Prescription Drug, Improvement and Modernization Act of 2003.[284] Other types of payment reform included pay-for-performance programs and disease management programs.[285]

Although a more general critique of managed care and its ethical implications can be found in bioethical journals and books from the 1990s and early 2000s,[286] this literature has decreased ever since. From this historical perspective, assuming that the questions and ethical concerns raised in this Article were no more relevant after the managed care backlash, it could be argued that bioethicists found no reason to discuss or analyze these issues.[287] As ACOs have not yet led to new ethical challenges—whether similar to or different from those in the managed care era—it may be too soon to deal with these new challenges in the bioethical literature.

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[284] *Id.*

[285] James J. Mongan et al., *Options for Slowing the Growth of Health Care Costs*, 358 NEW ENG. J. OF MED. 1509, 1510 (2008).

[286] *See generally* WILLIAM B. BONDESON & JAMES W. JONES, THE ETHICS OF MANAGED CARE: PROFESSIONAL INTEGRITY AND PATIENTS RIGHTS (2003); Ruth R. Faden, *Managed Care and Informed Consent*, 7 KENNEDY INST. ETHICS J. 377 (1997); E. Haavi Morreim, *Moral Justice and Legal Justice in Managed Care: The Ascent of Contributive Justice*, 23 J.L. MED. & ETHICS 247 (1995); Charles J. Dougherty, *Managed Care and (Un)Informed Consent*, 12 J. HEAD TRAUMA REHABILITATION 21 (1997); Pellegrino, *supra* note 250. Haavi Morreim's seminal article on the requirements of financial disclosure and financial advocacy provides an example of a scholarly paper focusing on this subject from a legal perspective, as the author explores legal bases for supporting such duties. Despite its comprehensive analysis and relevance to the issue at stake, this Article, which was published in a legal journal, does not fall under my definition of "bioethical literature" in *supra* note 250. *See* E. Haavi Morreim, *Economic Disclosure and Economic Advocacy*, 12 J. LEGAL MED. 275 (1991) [hereinafter Morreim, *Economic Disclosure and Economic Advocacy*]. Morreim's later writings on the issue also focus on the legal aspects and implications of financial disclosure (mainly through torts and contract law) and will also not be considered as bioethical analyses of the topic. *See* E. Haavi Morreim, *High-Deductible Health Plans: New Twists on Old Challenges from Tort and Contract*, 59 VAND. L. REV. 1207, 1213 (2006); E. Haavi Morreim, *High-Deductible Health Plans: Litigation Hazards for Health Insurers*, 18 HEALTH MATRIX 1, 8 (2008).

[287] Since the venues in which bioethics scholars choose to publish a particular article are partly affected by considerations of which audience they are more likely to reach, a more complex argument is in place. However, such an argument is beyond the scope of this Article.

B. The Relationship Between Ethics and Law

This section argues that, despite the great importance of the legal changes in the doctrine of informed consent in the light of the organizational and financial reforms of the health system, the bioethical literature has shown little interest in these changes due to the complex relationship between ethics and law and the substantial differences between these two normative realms. This explanation is further divided into the following four sub-explanations.

1. *Legal Changes Are of No Interest to Ethics*

One can argue that although ethics and law have much in common and frequently involve similar normative positions, ethics are and should be distinguished from law.[288] According to this argument, the ethical analysis of informed consent is a separate discourse from the legal one, so that even if the legal doctrine were to change substantially, this would not necessarily entail a similar interest on the part of ethicists exploring this issue. It follows that ethics focuses on the general development of the principle of informed consent and its philosophical justifications, and may not necessarily be interested in incremental, minor, or contingent revisions to such principles that are the work of judges and politicians who may also be influenced by their own institutional interests.

2. *Legal Changes Are Unfamiliar to Ethicists*

According to this argument, ethicists are not aware of the recent legal changes in the doctrine of informed consent, not only

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[288] For a discussion on this topic and relevant references, see Sperling, *supra* note 4, at 58–59.

because they are usually uninformed about legal cases and legislation that do not trigger public debate,[289] but also because these changes are accompanied by the rhetoric of protection and promotion of patient autonomy and avoidance of paternalism—a view that ethicists already advocate.[290] Moreover, these legal changes occasionally appear as obiter dicta[291] and do not affect the final judgment of the cases in which they are presented. At other times they refer to ethical codes and principles as support, creating the false impression that these legal changes can be valid from an ethical perspective. It follows that while judges and legislators offer substantial changes to the doctrine of informed consent, they do this in a way that masks their intentions and the outcomes deriving from them. [292]

3. *Different Rationales for Informed Consent*

Another way to explain why ethics show such little interest in the recent legal changes in the doctrine of informed consent would be to argue that law and ethics have different rationales for this doctrine. Thus, while the legal rationales for informed consent are what this Author calls "intrinsic," namely, that the principle of informed consent can be justified by the inherent values attached to it, the rationales for informed consent offered by the bioethical and ethical literature are instrumental, namely, that the principle of informed consent can be justified by its contribution to the promotion of values that are not necessarily attached to it. Indeed, legal scholars and judges equate the doctrine of informed consent with the protection of two basic rights: to autonomy and to bodily integrity.[293] Hence, for example, in the sixth and most updated

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[289] *Id.* at 58.

[290] *See generally* John Coggon & Jose Miola, *Autonomy, Liberty, and Medical Decision-Making*, 70 Cambridge L.J. 523 (2011).

[291] PAUL RAMSEY, THE PAITENT AS PERSON: EXPLORATION IN MEDICAL ETHICS at xxvi (2002).

[292] Coggon & Miola, *supra* note 290, at 524.

[293] However, compare with Capron, who mentions six functions that the doctrine of informed consent serves: protecting personal autonomy; protecting the patient's status as a human being; avoiding fraud or duress; encouraging doctors to carefully consider their decisions; fostering rational decision-making

edition of *Fundamentals of Health Law*, Barry Alexander and colleagues start their discussion of the doctrine of informed consent by referring to "the right to be free of undesired personal contact."[294] Nonetheless, when writing that *such a right* is fundamental under United States law, they refer to the right to autonomy and the concept of self-determination.[295] Similarly, in their *Health Care Law and Ethics in a Nutshell*, Mark Hall and colleagues write that the core value underlying the law of informed consent is autonomy.[296] According to this view, "informed consent seeks to place patients in control of the course of their medical treatment."[297] Likewise, Barry R. Furrow and colleagues refer to both the values of autonomy and bodily integrity when they write in their sixth and recent edition of *Health Law: Cases, Materials and Problems* that "informed consent was developed out of strong judicial deference toward individual autonomy, reflecting a belief that an individual has a right to be free from nonconsensual interference with his or her person, and a basic moral principle that it is wrong to force another to act against his or her will."[298] This view is also reflected in case law. The right to make free choices regarding one's body was legally developed in *Schloendorff v. Society of NY Hospital*, in which the court that held that "every human being of adult years and sound mind has a right to determine what shall be done with his own body."[299]

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by the patient; and involving the public generally in medicine. Alexander M. Capron, *Informed Consent in Catastrophic Disease Research and Treatment*, 123 U. PA. L. REV. 340, 364–76 (1974).

[294] ALEXANDER ET AL., *supra* note 13, at 63.

[295] *Id.* "No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." Union P. R.R. Co. v. Botsford, 141 U.S. 250, 251 (1891).

[296] HALL ET AL., *supra* note 16, at 314.

[297] *Id.* at 125.

[298] FURROW ET AL., *supra* note 109, at 240.

[299] Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914) (majority opinion written by Justice Cardozo).

In contrast, the bioethical literature discussing the justifications for informed consent reveals that, unlike the legal conceptualization of informed consent, this doctrine does not have inherent value. Rather, it serves as a means to promote other values external to it, although it may not necessarily be sufficient for this purpose.[300] Hence, in such a view, informed consent is justified for its enhancement of patient well-being,[301] liberty,[302] non-maleficence (avoidance of deception),[303] bodily integrity (ownership)[304] and respect for persons (human dignity).[305]

According to this analysis, the legal changes in the doctrine of informed consent are based on its intrinsic justifications. Under these justifications, as long as the patient has an opportunity to choose his or her course of action freely (autonomy), and because narrowing the scope of disclosure does not result in bodily violation, these legal changes are valid and can be supported from the legal perspective. Moreover, the disclosure of physicians' financial interests (even if it is limited) does not aim at deliberately harming the patient[306] or deceiving her.[307] Disclosure does not lead to decrease in patient freedom or level of respect (whether objective or subjective). Moreover, ownership over one's own body is not threatened or otherwise endangered. It follows that the legal changes in the doctrine of informed consent are also valid and can be

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[300] Natalie Stoljar argues that informed consent is insufficient and inadequate to ensure that the patient will indeed exercise her preference, that is, her autonomy. *See generally* Natalie Stoljar, *Informed Consent and Relational Conceptions of Autonomy*, 36 J. MED. & PHIL. 375, 382 (2011).

[301] James Stacey Taylor, *Autonomy and Informed Consent: A Much Misunderstood Relationship*, 38 J. VALUE INQUIRY 383, 390–91 (2004).

[302] Shlomo Cohen, *The Gettier Problem in Informed Consent*, 37 J. MED. ETHICS 642, 644 (2011); Katz, *supra* note 1, at 83; Lars Ursin, *Personal Autonomy and Informed Consent*, 12 MED. HEALTH CARE & PHIL. 17, 22 (2009); GERALD DWORKIN, THE THEORY AND PRACTICE OF AUTONOMY 108 (1988).

[303] ONORA O'NEILL, AUTONOMY AND TRUST IN BIOETHICS 160 (2002); Onora O'Neill, *Some Limits of Informed Consent*, 29 J. MED. ETHICS 4, 6. (2003).

[304] David Archard, *Informed Consent: Autonomy and Self-Ownership*, 25 J. APPLIED PHIL. 19, 27–31 (2008).

[305] Sigurdur Kristinsson, *Autonomy and Informed Consent: A Mistaken Association?*, 10 MED. HEALTH CARE & PHIL. 253, 262 (2007).

[306] Taylor, *supra* note 301, at 390–91.

[307] O'Neill, *supra* note 303, at 5.

supported externally (from an ethical perspective), and this is the reason why the bioethical literature has so little interest in them.[308]

4. *The Distinction Between Positive and Negative Rights*

Another way to address the different views of law and ethics about the recent changes in informed consent is to argue that while the legal right to be informed is interpreted as a positive right and thus subject to scarcity of time and resources, ethics conceptualizes such a right negatively, specifically, as free from such limitations.

The positive/negative right distinction is based on Charles Fried's writing on the subject. Fried argues as follows:

> A positive right is a claim to something, a share of material goods, or some particular good like the attention of a lawyer or a doctor or perhaps the claim to a result like health or enlightenment, while a negative right is a right that something not be done to one, that some particular imposition be withheld. Positive rights are inevitably asserted to scarce goods, and consequently scarcity implies a limit to the claim. Negative rights, however, the rights not to be interfered with in forbidden ways, do not appear to have such natural, such inevitable limitations . . . [309]

Fried continues, "It is logically possible to respect any number of negative rights without necessarily landing in an impossible and

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[308] O'Neill, *supra* note 303; Taylor, *supra* note 301.

[309] CHARLES FRIED, RIGHT AND WRONG 110 (1978).

contradictory situation . . . Positive rights, by contrast, cannot as a logical matter be treated as categorical entities, because of the scarcity limitation."[310]

However, as the philosophers Cécile Fabre and Henry Shue argue, such a distinction is problematic and may not always be valid. In Fabre's view, the intuition that some rights are only negative while others are only positive should be called into question. The right to freedom of speech, for example, forms the basis for the obligation to avoid censoring others, but is also a right to be given means to express ourselves.[311] In Shue's view, the rights ordinarily thought of as negative ones in fact ground positive duties, while rights which are often thought of as positive ones ground negative as well as positive duties.[312] For example, the demand for physical security is not normally a demand simply to be left alone, but a demand to be protected against assaults upon one's physical security.[313] Similarly, the right to subsistence forms the basis for the state's duty to help us by giving us food, as well as others' obligation not to threaten our means of subsistence.[314]

Even if the distinction between positive and negative rights is valid, it should not necessarily be assumed that only positive rights are subject to resource limitations. As argued above, the legal understanding of informed consent is not necessarily perceived as protecting positive rights, because the inherent values of informed consent involve patient autonomy and bodily integrity—both of which are negative rights under Fried's classical classification. It follows that the distinction between positive and negative rights and its possible implications may not serve to explain why ethics has so little interest in the recent legal changes in informed consent.

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[310] *Id.* at 113.

[311] Cécile Fabre, *Constitutionalising Social Rights*, 6 J. POL. PHIL. 263, 270–71 (1998).

[312] *Id.* at 273.

[313] HENRY SHUE, BASIC RIGHTS: SUBSISTENCE, AFFLUENCE, AND U.S. FOREIGN POLICY 38–39 (2d ed. 1980); *but see* Deshaney v. Winnebago Cnty. Dep't of Soc. Servs., 489 U.S. 189, 196–97 (1989) (holding that the Due Process Clause imposes no affirmative obligation on the State to provide the general public with adequate protective services).

[314] SHUE, *supra* note 313, at 52.

C. The Money Taboo and the Bioethical Literature

1. *The Main Argument*

While all or some of the above explanations may work well, they do not provide a convincing answer as to why changes in the most prominent doctrine in bioethics, which have such a strong influence on the way physicians, HMOs, and patients behave in this new era because they derive from the normatively high position of the United States Supreme Court, nevertheless receive so little attention and discussion in the ethical literature. A stronger claim would be to argue that the lack of interest in legal changes in informed consent derives from doctors' and patients' reluctance to discuss money, and the construction of the bioethical discussion in a way that perpetuates this reluctance. Using the term "money taboo" coined by the medical sociologist Howard Stein—namely the moral ban on physicians concerning themselves with financial matters in their professional role[315]—this Author argues, like Stein (and others[316]), that physicians' attitudes to monetary issues are highly ambivalent. On the one hand, physicians are trained to give rather than receive, and reciprocity between physicians and patients is merely implicit, yet the public expects physicians to lead a life of self-sacrifice, although they accept the fact that they flaunt their income with expensive homes and luxury cars. On the other hand, physicians seek to earn a comfortable living following tremendous sacrifice during their education, yet they minimize and even

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[315] Howard F. Stein, *Part 1: The Money Taboo in American Medicine*, 7 MED. ANTHROPOLOGY 1, 2 (1983).

[316] *See generally* ELI GINZBERG, THE ECONOMIST AS A PUBLIC INTELLECTUAL (Eli Ginzberg & Irving Louis Horowitz eds. 2002). "The literature on medical ethics simultaneously places the practitioner above mere money, and at the same time established rules of behavior to help physicians make money." David J. Rothman, *Money and Medicine: What Should Physicians Earn/Be Paid?*, *in* GINZBERG, *rsupra* note 316, at 109.

disavow the importance of recompense in their lives. Societally, argues Stein, physicians are regarded as both rewarded and punished for their monetary interests.[317] Stein stated, "caught in the unrelenting 'double-bind' of the social transference, the very profession which stands accused of being consumed with interest in money must behave as though disinterested in anything monetary while pursuing the good life."[318]

Stein's powerful argument about the culture of medicine still holds today. Although many physicians, especially younger ones, are more overtly interested in monetary compensation, they rarely discuss this directly with patients, but instead leave it to the business office or insurance company. It is the exceptional physician who performs her duty of what Havii Morreim calls "economic advocacy,"[319] namely, working directly with patients and the business office to help the patients with the cumbersome paperwork needed to obtain, for instance, free medications from the pharmaceutical company or some reduction in co-payment.[320] When entering data into the computer, or writing on the charge ticket, the physician merely indicates the level of service provided to the patient in terms of its complexity, time spent, etc. However, he or she does not include the dollar amount for that service. Even today it is the business office personnel who do the "coding" that is, enter the specific code that indicates the level of service, procedure performed, etc.[321] All of these observations

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[317] Stein, *supra* note 317, at 7.

[318] *Id.* at 7–8. Compare also with Rothman who argues that "patients were happy to tap into a tradition that put physicians as professionals above money (delaying payment accordingly), but they also insisted that physicians as consumers accept marketplace rules and play by them." Rothman, *supra* note 316, at 113.

[319] *See* Morreim, *Economic Disclosure and Economic Advocacy*, *supra* note 286.

[320] *But see* Christopher Moriates et al., *First, Do No (Financial) Harm*, J. AM. MED. ASS'N. E1 (July 2013), *available at* http://jama.jamanetwork.com. Arguably, when systematic utilization review and management began during the 1980s and 1990s, many physicians spent enormous amounts of time advocating for their patients, and the physicians hired office personnel whose sole role was to argue with insurers in order to get medical procedures covered. *Id.*

[321] In addition to the argument from the physician's role and involvement in monetary issues, part of the reason for this derives from the financial complexity of the American healthcare system. Specifically, since most of the patients do not pay the "rack rate" price but the insurer-discounted

support Stein's argument about the money taboo, whatever its sources.[322]

On the one hand, as a dominant institution in society, the medical profession is a party to the more general paradoxical attitude of society and social scientists toward money. As Viviana Zelizer points out, "Although money is considered a basic element of modern society, as a sociological category it remains unanalyzed. . . .As a result it is confined primarily to the economists' domain."[323] On the other hand, the dramatic changes in the structure of the health care system, specifically the evolving and the more legitimate role that money plays in medicine and the great political power of healthcare systems, limit the extent to which bioethical discussions reflect upon, criticize, and scrutinize these changes. As Carl Schneider rightly suggests, bioethics was and still is a reform movement.[324] But "it is a movement with an enemy—medical imperialism. Such movements welcome intellectuals only as long as they are politically useful; they loathe renegades."[325]

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price, the doctor's office would have to know a great deal about each individual patient's insurance plan before the doctors could even begin to discuss the price of any kind of intervention. Also, the financial arrangements between an individual physician and any particular insurance plan can be incredibly complex. Physicians often have contracts with numerous payers and MCOs. Such complexity is reemerging, although in a simpler way, as more physicians are being hired by hospitals, as their practices are becoming exclusively aligned with a single hospital and as more patients join ACO health plans.

[322] Stein does not develop the idea of the money taboo but merely describes it based on his ethnographic experience. The idea can be supported by reference to the main arguments opposing commodification of care under the assumption that talking about money is as bad as having monetary interests and activities. Stein, *supra* note 315. These arguments focus on the corrupting effect that money has on the caring relationship and the way it hinders the personal relationship necessary to sustain good caring activities. *See generally* Rutger Claassen, *The Commodification of Care*, 26 HYPATIA 43 (2011).

[323] VIVIANA A. ZELIZER, THE SOCIAL MEANING OF MONEY: PIN MONEY, PAYCHECKS, POOR RELIEF, AND OTHER CURRENCIES 1, 4 (1997).

[324] Schneider, *supra* note 269, at 413.

[325] *Id.* at 413–414.

If the above description is correct, it implies that it is immoral to sell services or affix price tags to services at the time of transaction, just as it is impermissible to discuss cost issues with patients, especially at time of treatment. On the other hand, it may be morally acceptable to leave the "dirty job" of discussing money issues to the healthcare organization or health plan, to be implemented only at the moment of enrollment into a health plan.

Not only does the money taboo resonate in the culture of medicine, but it is also vivid in the bioethical literature, and this literature is concerned with keeping it alive. The bioethical literature discussing issues such as managed care, trust, professionalism, physicians' and researchers' conflicts of interest, and the like not only assumes that the money taboo is a major part of the physician-patient relationship but also supports this taboo in the choice, organization, and content of its writings. Moreover, some of this literature further holds that bioethical discussions of medicine deserve precedence over monetary analysis of such issues.[326] This is one reason why most bioethicists object to cost-benefit analysis.[327] In the prevalent view, virtuous physicians earn sufficient income to provide their families with all necessities but do not devote themselves to becoming wealthy.[328] In the Author's view, this argument provides the most convincing explanation for the lack of discussion and criticism of changes made in the requirement of informed consent in the era of managed care, privatization and ACOs.

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[326] *See* Pellegrino, *supra* note 250, at 322; *see also* Rothman, *supra* note 316, at 109. However, this is not to argue that physicians do not have a moral obligation not to waste the patient's money, to use society's resources efficiently and not offer or provide unnecessary treatment. It also does not follow that rationing cannot be morally justified under some conditions. Pellegrino, *supra* note 250, at 323. *But see generally* E. Haavi Morreim, *Fiscal Scarcity and the Inevitability of Bedside Budget Balancing*, 149 ARCHIVES INTERNAL MED. 1012 (1989); E. Haavi Morreim, *Cost Containment: Challenging Fidelity and Justice*, 18 HASTINGS CTR. REP., Dec. 1988, at 20; Peter A. Ubel, *Physicians' Duties in an Era of Cost-Containment: Advocacy or Betrayal?*, 282 J. AM. MED. ASS'N. 1675 (1999).

[327] Schneider, *supra* note 269, at 414–15.

[328] Rothman, *supra* note 316, at 108–09.

2. *Support for the Main Argument*

This final section of the Article discusses some of the major bibliographical sources for the argument that the money taboo is assumed and strongly supported by the bioethical literature. While it may be difficult to consider the bioethical literature as a whole,[329] and the analysis of this literature deserves a separate article, this section focuses on the main writings on the issue at various periods of time.

Reviewing the bioethical literature reveals three main areas in which the money taboo is assumed: whether health and health care can and should be commodities; the idea of trust in medicine; and physicians' conflicts of interest and possible corruption.

a. Health and Health Care as Commodities

One of the clearest sources for the money taboo in the bioethical literature is the writings of late Edmund Pellegrino. In a well-known article entitled, *"The Commodification of Medical and Health Care: The Moral Consequences of a Paradigm Shift from a Professional to a Market Ethic*," Pellegrino not only argued that the ethical consequences of commodification are harmful to patients, physicians, and society.[330] Under the market and commodification ethos, reward and penalty for doctors depend negatively on the clinical costs they incur and positively on meeting marketing goals and patient satisfaction. In such a view this *necessarily* leads to a

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[329] *Supra* note 286.

[330] Edmund D. Pellegrino, *The Commodification of Medical and Health Care: The Moral Consequences of a Paradigm Shift from a Professional to a Market Ethic*, 24 J. MED. & PHIL. 243, 244 (1999).

loss of professionalism.[331] While in a commodity transaction the persons who buy and sell have no personal interest in each other beyond the transaction, the medical relationship is intensely personal and characterized by confidence and trust.[332] In the commodity model, writes Pellegrino, there is no economic justification for the extra time required to explain, counsel, comfort, or educate patients and their families, since these cost more than they return in revenue.[333] Unlike other personal services such as legal or ministerial advice, "the universality, unpredictability, inevitability, and intimate nature of the assault of illness on our humanity, the impediments it generates to human flourishing and the intimate and personal nature of healing give health care a special place even among the helping professions".[334]

In this view, by accepting the privilege of practicing medicine, medical and nursing students enter into an implicit covenant with society to use their knowledge for the benefit of the sick. The fees they charge and the compensation they receive are not for the knowledge they have, but for their time and effort in applying this knowledge to particular persons. Referring to Plato's *Republic*, Pellegrino argues for a view under which true physicians are healers first and moneymakers second.[335] In such a view stewardship is a better conception than proprietorship for medical knowledge and skill. Pellegrino concludes,

> What is equally crucial is that the physician remain truly a physician, concerned with healing and not money-making. In any plan in the future, the physician ought not be the gatekeeper, microallocator, or rationer. Nor should she or he become provider, insurer, or risk-taker simultaneously. The current move to establish the

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[331] *Id.* at 245.
[332] *Id.* at 249.
[333] *Id.* at 253.
[334] *Id.* at 249.
[335] *Id.* at 251.

> physician-provider organizations in which employers, hospitals, and corporations "buy" health care from groups of doctors are just as dubious morally as other capitated insurance plans. In addition, they deprive patients of their last advocate since the physician is the healer, the risk-taker, and the profit-maker simultaneously.[336]

b. Trust in Medicine

The idea of the money taboo is also present in bioethical discussions of trust in medicine. A common theme in such discussions is that patients trust their physicians to care for them, but this trust is conditional on the latter being completely loyal to them. Under this substantial approach to trust in medicine, being loyal to one's patients requires discussing only medical issues with the patient, and avoiding any other considerations, including financial ones or those involving the interests of third parties or society as a whole.

For example, reflecting on the aims of medicine, Daniel Palmer argues that the physician has the health of her patients as her primary aim, so that all other aims a physician may have in practicing medicine are constrained by the pursuit of her aim of promoting the health of her patients.[337] Similarly, Daniel Sulmasy holds that a policy in which physicians are restrictive gatekeepers disrupts the trust central to the doctor-patient relationship.[338] This is because such a policy "will have transformed a relationship in which

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[336] *Id.* at 262.

[337] Daniel E. Palmer, *Individual Goods, Collective Goods, and the Aims of Medicine*, 40 J. VALUE INQUIRY 243, 244 (2006).

[338] Daniel P. Sulmasy, *Physicians, Cost Control, and Ethics*, 116 ANNALS INTERNAL MED. 920, 920 (1992).

a physician has traditionally been regarded as a patient advocate into one in which the patient and the physician assume adversarial roles in a struggle between proximate economic rivals."[339]

In line with this traditional thinking, Gregg Bloche claims that when physicians involved in patient care engage in financial decision-making and gatekeeping, this leads to a problem of conflicting clinical obligations.[340] In Bloche's view, the new form of gatekeeping "explicitly challenges the premise that physicians should act toward their patients as faithful fiduciaries."[341] This duty of undivided loyalty to patients, rooted in the Hippocratic Oath, prevents physicians from having discussions with their patients about any issues not strictly pertaining to their direct care. Bloche writes,

> The Hippocratic promise of uncompromising loyalty to patients has kept us from starting a candid conversation about medicine's expanding public roles. It shames doctors from admitting, even to themselves, that they serve social purposes, sometimes at their patients' expense. And it encourages citizens to expect their doctors to disregard the common good. The result is near-silence about medicine's social uses—and an inability to discuss the drawing of lines between acceptable and intolerable public purposes.[342]

A different approach to trust in medicine, which puts an emphasis on the procedures leading to trust rather than on the content associated with the idea of trust, can be found in the writings

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[339] *Id.* at 922.

[340] M. Gregg Bloche, *Clinical Loyalties and the Social Purposes of Medicine*, 281 J. AM. MEDICAL ASS'N 268, 268 (1999).

[341] *Id.* at 269.

[342] BLOCHE, *supra* note 244, at 10.

of Allen Buchanan.[343] Distinguishing between status trust and merit trust, Buchanan considers the proposition that managed care creates a shift toward a greater role of derivative merit trust, namely trust in physicians derived from the institutions and organizations in which they practice.[344] In his view, while traditional medical ethics, which promotes the importance of doing what is in the best interest of the patient, cannot support status trust in an era of scarcity when each physician treats many patients, managed care patients can still sustain primary trust in their physicians if and when the latter exhibit certain "caring behaviors."[345] This may be possible by grounding merit trust in the legitimacy of the organization.

One way to do this, Buchanan argues, is to satisfy procedural justice requirements, specifically to have the managed care organization publicize institutional policies outlining rationing practices and the justifications for them. Buchanan argues that disclosure of physician risk-sharing is required not only because of the wrong incentives or their magnitude on care but because "a legitimate managed care organization is one that accommodates the distinctive fiduciary obligation of the physician, and disclosure of physician risk sharing is necessary if patients are to be able to judge whether this condition of legitimacy is met."[346] While Buchanan argues that the physician should be a "critical cooperator" and in some cases an advocate for her patients, e.g., serving as their representative in the appeals process when a policy denies care that can be reasonably expected to provide some net benefit and by

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[343] *See* Allen E. Buchanan, *Trust in Managed Care Organization*, 10 KENNEDY INST. ETHICS J. 189 (2000).

[344] *See id.*

[345] *Id.* at 194. *Compare* this view with that of Edmund Pellegrino. Edmund D. Pellegrino, *Trust and Distrust in Professional Ethics*, *in* EDMUND D. PELLEGRINO ET AL., ETHICS, TRUST, AND THE PROFESSIONS: PHILOSOPHICAL AND CULTURAL ASPECTS 69 (1991).

[346] Buchanan, *supra* note 344, at 198.

informing the patient if the care that is being denied is available elsewhere, this should only be allowed when the organization provides the conditions for legitimacy and evidences a capacity for and a commitment to improvement in legitimacy, thereby supporting physicians' distinctive non-instrumental commitment to patients' well-being.[347] It follows that the disclosure of financial incentives and of care rationing should be a pre-condition for a patient to trust the organization, as well as the physicians working within it. It is thus ethically required of the organization rather than the physician to discuss these issues with patients.

Along these lines, Robert Sade, writing on markets and health, likewise argues that the critical difference between medicine and other professions and services is "the idea of effacement of self-interest in favor of serving primarily the patient interests or the patient good."[348] Referring to Buchanan, Sade contends that if there are appropriate organizational policies providing the patient with sufficient information to choose among all available options and plans, the dyadic healing relationship between physician and patient can be respected.[349]

c. Physicians' Conflicts of Interest and Possible Corruption

An extension of the substantial approach to trust in medicine results in a more refined notion of physicians' conflicts of interests. Such a notion, primarily developed by Marc Rodwin, holds that the new era has brought about substantial institutional changes, thereby reshaping the characteristics of physicians' conflicts of interest.[350]

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[347] *Id.* at 201–02.

[348] ROBERT M. SADE, *Medicine and Managed Care, Morals and Markets*, *in* THE ETHICS OF MANAGED CARE: PROFESSIONAL INTEGRITY AND PATIENT RIGHTS 55, 61 (William B. Bondeson & James W. Jones eds., 2002).

[349] *Id.* at 65.

[350] Marc A. Rodwin, *Conflicts of Interest and Accountability in Managed Care: The Aging of Medical Ethics*, 46 J. AM. GERIATRICS SOC'Y. 338, 338 (1998).

Specifically, the new system has compromised the physician's exercise of independent judgment and loyalty to the patient, and limited clinical autonomy by exposing physicians to more scrutiny by both the profession and the public, thereby undermining their duty to act in the best interest of their patients.[351] According to this notion, the problem of physicians' conflicts of interest is ethically disturbing not only because physicians have an incentive to reduce services even when it is in the patient's interest to receive them, but also—and more relevant to this Article—because this new organization of services, by restricting and excluding various forms of care due to financial considerations, reduces patients' informed choice, since most people cannot understand the implications of these restrictions or exclusions. Moreover, various policies that encourage physicians to avoid discussing some treatment options increase their risks and decrease their benefits, and in some cases prohibit physicians from informing patients about the existence of such options and make it difficult for the physicians to reconcile their conflicting obligations—on the one hand, their ethical and legal duty to inform patients of clinical options and risks and allow them to choose from among them, and, on the other hand, their obligation to follow the organizational policies that limit patient choice.[352]

An additional step in the analysis of physicians' financial obligations and duties toward their patients is looking at some of the financial obligations as leading to corruption. In a chapter entitled, "A Crisis in Medical Professionalism: Time for Flexner II," Daniel Wikler claims that the integrity of American medicine is seriously threatened by an epidemic of conflicts of interest whose symptoms

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[351] *See generally id.*

[352] Marc A. Rodwin, *Conflicts in Managed Care*, 332 NEW ENG. J. MED. 604, 605 (1995).

are the corruption of the medical mission and ideals.[353] Referring to the transformation, compromise, and undermining of the medical profession by the drug industry and other commercial interests, Wikler highlights the vast influence of pharmaceutical corporations and other for-profit health organizations on physicians, medical educators, scholars, editors, and the like, and the possible public health consequences deriving from it.[354] He writes, "[t]he basis for medicine's claim to be a profession rather than a trade, exchanging a degree of self-governance and autonomy to trusted experts, is the assurance that this trust will not be misplaced."[355]

Under this analysis, failure to inform patients of physicians' competing interests not only puts them in an ethically disturbing state of conflict of interests, as argued by Rodwin, but corrupts them morally, thereby seriously undermining the integrity of the medical profession and, in some cases, exposing the public health to serious threats and possible harm.

IX. CONCLUSION

Putting aside the differences between the American and Israeli health systems, this Article described and discussed recent substantial revisions to the legal requirement of informed consent and the settings in which this requirement is applied in both countries. These changes demonstrate a gradual decline in the physician's duty to disclose information material to the patient's decision and the limitation of this duty by new factors such as the treatment setting, source of payment, financial incentives for the physician, cost and time constraints, and the broader context of the healthcare system. All these changes have occurred in an era when physicians are being put under increasing pressure to take into

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[353] *See generally* Daniel Wikler, *A Crisis in Medical Professionalism: Time for Flexner II*, *in* DENIS G. ARNOLD, ETHICS AND THE BUSINESS OF BIOMEDICINE 249 (2009).

[354] *Id.* at 250.

[355] *Id.* at 253. Compare that with a recent study showing that 94% of American doctors have some relationship with a drug or medical device company. Eric G. Campbell et al., *A National Survey of Physician-Industry Relationships*, 356 NEW. ENG. J. MED. 1742, 1746 (2007).

consideration financial and organizational factors, and to act under the constraint of managed care organizations, ACOs, and the increased privatization of health services.

Given a prima facie duty to disclose the physician's financial interests to the patient, and not restrict or otherwise limit this duty, it was argued that, paradoxically, the bioethical literature has shown very little interest in these important legal changes in the doctrine of informed consent. Two major arguments were suggested to explain why this is so: the first involving the managed care backlash; and the second, the complex relationship between ethics and law. The latter argument suggested four alternative directions for thinking about this relationship: that legal changes are of no interest to ethics; that legal changes are unfamiliar to ethicists; that every discipline has different rationales for the doctrine of informed consent; and that the different approach taken by each discipline is attributable to the distinction between positive and negative rights.

It was further argued that while all or some of the above explanations may work well, they do not provide a convincing answer as to why changes in such an important legal and ethical doctrine, namely the doctrine of informed consent, receive so little attention and discussion in the ethical and, specifically, bioethical literature. A stronger claim in this respect is the argument that the lack of interest in legal changes in informed consent derives from physicians' and patients' reluctance to discuss money, conceptualized as "the money taboo," and the constriction of the bioethical discussion in a way that preserves and perpetuates this reluctance. Three areas of discussion in the bioethical literature were presented in the Article to demonstrate how the money taboo is assumed and considered in various discussions. These include the question of whether health and health care can and should be commodities, the idea of trust in medicine, and the issue of physicians' conflicts of interests and corruption.

Analyzing the issue of the money taboo in the bioethical literature has far-reaching implications for the way writings in this literature should be interpreted and evaluated. On a more immediate level, it shows that ethics and ethicists play a significant role in preserving taboos and myths about the intersection of money and medicine and the protection and promotion of interests external to the therapeutic relationship. It demonstrates that major actors in the bioethical arena are unable to fully and courageously discuss the drawing of lines between acceptable and intolerable actions of physicians when they are involved with money issues and, more generally, social considerations such as time and resource allocation. This is how ethical discussions avoid money, time, and resource considerations and the problematic re-constitution of the doctrine of informed consent.

AGEISM AND AUTOPSIES: THE CORONER COMBATTING ELDER ABUSE IN NURSING HOMES

Nicole S. Bell[*]

> "*Maybe I should have gone into geriatrics. No one minds when you kill an old person.*"
> -George O'Malley in *Grey's Anatomy*[**]

I. INTRODUCTION

Although each state's legislature is responsible for defining elder abuse for its state, elder abuse can generally be defined throughout the United States as "any knowing, intentional, or negligent act" by any person that causes some type of harm to an elder adult.[1] This may include physical, sexual, and emotional abuse, as well as neglect or financial exploitation.[2] Despite the lack of reliable information, many organizations have attempted to conduct studies in order to determine the amount of elder abuse occurring in the United States and other countries.[3] In the United States, it is estimated that roughly one in ten elders age 60 and older experience some form of abuse.[4] Of those abused, only one in fourteen will be reported to the proper authorities.[5]

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[*] Nicole Bell graduated from Stetson Law in May 2016 and currently practices in St. Petersburg, Florida, in estate planning, probate, and business planning.

[**] Grey's Anatomy: A Hard Day's Night (ABC television broadcast Mar. 27, 2005).

[1] Eldercare Locator, *Elder Abuse*, ELDERCARE.GOV, http://www.eldercare.gov/Public/Resources/Factsheets/Elder_Abuse.aspx (last visited July 8, 2019).

[2] *Id.*

[3] World Health Org., *Elder Abuse*, WHO.INC, https://www.who.int/news-room/fact-sheets/detail/elder-abuse (last visited July 8, 2019).

[4] Nat'l Council on Aging, *Elder Abuse Facts*, NCOA.ORG, https://www.ncoa.org/public-policy-action/elder-justice/elder-abuse-facts/ (last visited July 8, 2019).

[5] *Id.*

Although most elder abuse occurs within the family,[6] there is an alarming amount of abuse allegedly existing in nursing homes. "In a study of 2,000 interviews of nursing home residents, 44% said they had been abused and 95% said they had been neglected or seen another resident neglected."[7] Moreover, as the baby boomer generation exceeds the age of 65, there will be more elder persons entering nursing homes, which creates a growing fear that there may also be a growing elder abuse problem.[8] States within the United States and other countries vary on how they address the problem of nursing home abuse.[9] Despite numerous laws and regulations being enacted as an attempt to prevent nursing home abuse, abuse is still prevalent and still going undetected.[10]

Consider this hypothetical: Larry was 81 years old when his family admitted him into Sunny Oaks Nursing Home. Unfortunately, Larry was unable to live alone because he suffered from dementia and needed constant supervision. During the two years Larry lived in Sunny Oaks, his dementia rapidly declined to the point where he could barely communicate his needs to the staff, his doctors, or his family. Larry's family, who lived over eight hours away, rarely visited, but they believed the staff at Sunny Oaks to be helpful and kind to Larry. On the date of Larry's passing, the nursing home staff gently informed Larry's family, and the staff followed the family's instructions for removal of his body for burial. The family arranged for Larry's body to be sent to a funeral home in Larry's hometown. Larry's attending physician at Sunny Oaks listed the cause of death on the death certificate as "natural causes." When Larry's body arrived at the funeral home, the funeral director began to prepare the

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[6] *Id.*

[7] Nat'l Ctr. on Elder Abuse*, Fact Sheet: Abuse of Residents of Long Term Care Facilities*, CENTER OF EXCELLENCE ON ELDER ABUSE AND NEGLECT (Feb. 2012), http://www.centeronelderabuse.org/docs/Abuse_of_Residents_of_Long_Term_Care_Facilities.pdf.

[8] Nat'l Ctr. on Elder Abuse, *Abuse of Residents of Long Term Care Facilities*, NCEA, http://eldermistreatment.usc.edu/wp-content/uploads/2017/02/NCEA_ResidentsLTCF_ResearchBrief2012.pdf (2012).

[9] *See infra* pt. III (describing mandatory reporting laws, nursing home staff requirements for background checks, training, and education, and electronic monitoring all designed to combat nursing home abuse).

[10] *See infra* pt. III (describing factors that make identification and prosecution of nursing home abuse difficult despite laws and regulations enacted to prevent such abuse).

body for burial when he noticed abnormal bruising on the body. The funeral director hesitantly contacted the local authorities and explained his concerns. The authorities instructed him to send the body to have an immediate autopsy performed. The autopsy results told a much different story than the death certificate. Larry's true cause of death had been from severe dehydration, pneumonia, and sepsis.

When an elder person's death occurs in a nursing home,[11] the odds of abuse being discovered and reported after-the-fact drastically reduces.[12] Abuse that causes death is best discovered through autopsy. For example, if a resident died from internal hemorrhaging, an autopsy would indicate whether the elder person fell out of bed or was shoved out of bed. Due to the vulnerability of elder persons living in nursing homes, jurisdictions should adopt laws similar to states like Arkansas[13] that require all deaths occurring in nursing homes to be medically examined through autopsy. An autopsy is a post-mortem examination to determine the cause and manner of death.[14] By requiring all deaths occurring within a nursing home to be reported to the appropriate coroner[15] for autopsy,[16] states can detect if an elder person's death was caused by

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[11] Nat'l Ctr. on Elder Abuse, *supra* note 6. A nursing home is one type of a long-term care facility. *Id.* Long-term care facilities usually include assisted living facilities or nursing homes. *Id.* Most of the discussion in this Article could also apply to long-term care facilities.

[12] CARMEL BITONDO DYER ET AL., *The Clinical & Medical Forensics of Elder Abuse & Neglect, in* ELDER MISTREATMENT: ABUSE, NEGLECT, & EXPLOITATION IN AND AGING AMERICA 12 (Bonnie RJ & Wallace RB eds., 2003).

[13] ARK. CODE ANN. § 12-12-1709(a)(1) (2019).

[14] BLACK'S LAW DICTIONARY 161 (Bryan A. Garner ed., 10th ed. 2014).

[15] Since the role and responsibilities of a coroner vary by jurisdiction, a coroner will be defined as an individual who is a licensed forensic pathologist for purposes of this Article. If the term "coroner" is used in another jurisdiction's context, that jurisdiction's definition of coroner shall apply.

[16] There are various names and titles for persons who perform autopsies: coroner, undertaker, medical examiner, pathologist, and mortician. The title of the person conducting the autopsy may indicate several things; however, this can vary greatly by the laws of each jurisdiction. *See* Sandra Bartlett, *Coroners Don't Need Degrees to Determine Death,* NPR (Feb. 2, 2011, 12:06 PM ET), http://www.npr.org/2011/02/02/133403760/coroners-dont-need-degrees-to-determine-death. First, the title may indicate the degree and education of the person conducting the autopsy. For example, a coroner does not need a medical degree, whereas medical examiners and pathologists do. *Id.* The title will also indicate the level or specialty of the education. *Id.* For example, a forensic pathologist will

abuse. This will deter intentional mistreatment of elders in nursing homes as well as provide additional protection by requiring nursing homes to implement better policies and procedures in caring for elders. Not only do laws like Arkansas's deter abuse, but they are also a reliable "last chance" measure to catch elder abuse that may have otherwise gone unreported or unnoticed.

This Article will focus primarily on the abuse of elder persons that results in death in nursing homes but remains undetected. It will begin by discussing the process that typically occurs when an elder person dies in a nursing home and how the death is reported on death certificates. Then, this Article will briefly explore the ways that states and other countries have responded to nursing home abuse and why each particular law fails to discover nursing home deaths caused by abuse. Finally, this Article will discuss the need for an autopsy to be performed after each nursing home death to prevent future abuse and punish the perpetrators.

II. PROCEDURE AND ANALYSIS OF A NURSING HOME DEATH

This part will guide the reader through the general processes that must be followed after an individual dies. Then, this part will highlight the weaknesses in those processes by reporting the poor standards in the practice of issuing death certificates that states and other countries require physicians to follow. This poor standard has led to two glaring concerns: erroneous death certificate completion and physicians with a conflict of interest completing death certificates. Given these concerns, it is exceptionally difficult for a physician to accurately and properly ascertain if an individual suffered from abuse and if abuse was the cause of an individual's death.

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have a specialty in determining causes and manners of death, whereas a general pathologist will have general knowledge on diseases and death. Lastly, the title will determine if a peer review is needed. *Id.* Coroners are more like an advocate for the deceased. A forensic pathologist will not need to be peer reviewed, unlike a medical examiner or general pathologist who will likely need to have peer reviews on their conducted autopsies. *See id.*

A. After-Death Procedures

In a nursing home, once an individual is pronounced dead by a physician, a staff member will contact a preselected family member of the decedent. That family member will decide, usually by following the decedent's wishes, where to send the decedent's body and whether to bury or cremate the body.[17] The funeral home, to assume first custody of the body, will collect personal and other important disposition information on the decedent. The funeral director will then forward the information to be indicated on the death certificate to a physician. In Florida, as in most states, the physician's main responsibilities are completing the medical certification portion on a death certificate and having relevant knowledge of the state statutes regarding causes of death.[18] The death must be registered with the state in accordance with its statutes.[19] The physician will complete the medical certification portion by marking the date, time, location, cause, and manner of death of the decedent.[20] This must be completed within 72 hours[21] in order to properly issue the death certificate. However, there are special circumstances that permit an extended period of time.[22] The

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[17] The decedent's wishes may be expressed to a family member through several ways, including verbal communication before death or by including a provision in the decedent's Last Will and Testament. Individuals are increasingly obtaining prepaid services from funeral homes indicating whether they want to be buried or cremated. *See* Nat'l Funeral Dirs. Ass'n, *Trends in Funeral Service*, NFDA.ORG, http://www.nfda.org/news/trends-in-funeral-service (last visited July 8, 2019).

[18] Bureau of Vital Statistics, *What the Physician Should Know About Certifying Cause of Death on the Florida Death Certificate*, FLA. HEALTH http://www.floridahealth.gov/certificates/certificates/EDRS/_documents/DH150-849MD_brochure.pdf (last visited July 8, 2019). The medical certification on the death certificate often includes reporting of the cause and manner of death. Medical certificates are used for other aspects in the medical field, however, the use of the medical certificate in this Article is limited to the use for death certificates.

[19] *Id.*; *see also* FLA. STAT. § 382.008 (2019).

[20] Bureau of Vital Statistics, *supra* note 18.

[21] *Id.* Florida requires the medical certification be completed within 72 hours, but other states will vary on their requisite time frame.

[22] *Id.* Extenuating circumstances that would allow issuance of a death certificate outside the requisite time frame may include a request by the attending physician or medical examiner. If such a

cause of death indicated on a death certificate will include the first condition causing death, any contributing causes, and any underlying cause or initiating disease.[23] The manner of death indicates whether the death occurred from natural causes, accident, homicide, suicide, or an undetermined cause.[24] Finally, the funeral director has the duty to file the death certificate with the appropriate office.[25] The death certificate may be filed on paper using a pre-approved form or it may be filed electronically on the Electronic Death Registration System.[26]

Most countries follow similar processes as to those commonly used in the United States, including Australia,[27] Scotland,[28] and Canada.[29] There are only a few deviations in the process, such as time frames for filing and what information to report on the death certificate or its equivalent. In Australia, there is a forty-eight-hour window for the doctor to complete the medical certification.[30] Should there be a "coronial inquiry," the death certificate will be filed but will be considered an "'incomplete' death registration."[31] More interestingly, Ghana, a developing country,

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circumstance arises, a Death Registration Delay Report (DRD Report) must be submitted by the funeral director or medical examiner to the correct person. A DRD Report should be used only in rare cases and when a death certificate cannot be submitted within the statutory time. Examples of this include the following: pending autopsy, pending lab reports, or if the identity of the decedent is unknown.

[23] *Id.*

[24] *Id.*

[25] *Id.*

[26] Fla. Vital Statistics, *Electronic Death Registration System: Completing the Medical Information*, FLA. HEALTH, http://www.floridahealth.gov/certificates/certificates/EDRS/_documents/EDRSBrochure2.pdf (last visited July 8, 2019).

[27] *See* Gov't of W. Austl., *Department of the Attorney General, Births, Deaths and Marriages*, GOV'T OF WESTERN AUST. http://www.bdm.dotag.wa.gov.au/R/register_a_death.aspx?uid=2504-0168-4804-8231 (last updated Feb. 8, 2018).

[28] *See* CIVIL & INT'L JUSTICE DIRECTORATE, WHAT TO DO AFTER A DEATH IN SCOTLAND (8th ed. 2008), *available at* http://www.gov.scot/Resource/Doc/213661/0056769.pdf.

[29] *See* OFFICE OF THE REGISTRAR GEN., MINISTRY OF CONSUMER & BUS. SERVS., HANDBOOK ON MEDICAL CERTIFICATION OF DEATH (2010), *available at* http://www.publications.serviceontario.ca/ecomlinks/016600.pdf.

[30] Gov't of W. Austl., *supra* note 27.

[31] *Id.*

has a very sophisticated and thorough means of reporting and investigating "unnatural" deaths. In Ghana, deaths that occur outside of a healthcare facility are considered to fall within the coroner's jurisdiction.[32] Coroners in Ghana are required to abide by the Coroner Act of 1960, which vests responsibility in the coroner to investigate unexplained deaths.[33] Unlike the United States and Scotland, which generally have similar processes, Ghana vests coroners the power to employ other personnel to assist him or her in the investigation of a death as well as determine his or her pay for such tasks. These personnel may include police officers, a registered medical practitioner, and a forensic toxicologist. Unlike Ghana, many other developing countries have almost no death registration process.[34]

China, which historically has kept very few death records, is currently in the process of developing and implementing an online death registration system.[35] China's population accounts for nearly one fifth of the world's total population, and it still does not have a firm grasp on its vital registration system.[36] The country is currently relying on a sample-based mortality system that hosts staff trained in health care to complete medical certifications in certain areas throughout the country.[37] Although they plan to establish a country-

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[32] J.T. Anim, *Autopsy Practice in Ghana—Reflections of a Pathologist*, 49 GHANA MED. J. 112, 113 (2015), *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4549826/ (As with most British colonized countries, the Coroner's Act was based off of England's Coroner's Act of 1887.).

[33] *Id.*

[34] *See* Chalapati Rao et al., *Improving Death Registration and Statistics in Developing Countries: Lessons from Sub-Saharan Africa*, 9 S. AFRICAN J. DEMOGRAPHY, Jun. 2004, at 81, *available at* https://www.commerce.uct.ac.za/Organisations/Demography/SA_Journal_of_Demography/SAJD/Volume%209%202/SAJDem_2004_9_2_Rao.pdf

[35] Lijun Wang et al., *Evaluation of the Quality of Cause of Death Statistics in Rural China Using Verbal Autopsies*, 61 J. EPIDEMIOLOGY & COMMUNITY HEALTH 519 (2007), *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2465713/.

[36] Shiwei Liu et al., *An Integrated National Mortality Surveillance System for Death Registration and Mortality Surveillance, China*, 94 BULL. WORLD HEALTH ORG. 46 (2016), *available at* http://www.who.int/bulletin/volumes/94/1/15-153148/en/.

[37] *Id.*

wide comprehensive plan, there are several concerns, such as the training of staff and uniformity between cities.[38] Also, in order to meet the high demand in population, China permits a cause of death to be identified through a verbal autopsy.[39] Despite strong efforts being put into place, China will have some challenges ahead, not only in creating a uniform system of death registration, but also in veracity of cause of death determinations.

B. Erroneous Death Certificates

In most states, each nursing facility has an attending physician (or multiple physicians) who provides medical assistance for the nursing home patients.[40] These attending physicians are essential to the care of the residents on a daily basis and the overall quality of the nursing home.[41] In most cases, the attending physician is also the certifying physician.[42] The certifying physician is the physician who completes and reports the medical certification portion on a death certificate.[43] Unfortunately, these physicians abide by inadequate standards of practice in reporting the medical certification for death certificate purposes.[44] These insufficient

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[38] *Id.*

[39] Ctr. for Global Health Research, *What Is Verbal Autopsy*?, CTR. FOR GLOBAL HEALTH RESEARCH, http://www.cghr.org/projects/million-death-study-project/what-is-verbal-autopsy/ (last visited July 8, 2019). A verbal autopsy is used when the medical examiner or the individual performing the autopsy has no medical records of the decedent, and the medical examiner or individual performing the autopsy must rely on verbal information from family or other reliable individuals, such as caretakers. World Health Org., VERBAL AUTOPSY STANDARDS: THE 2012 WHO VERBAL AUTOPSY INSTRUMENT, http://www.who.int/healthinfo/statistics/WHO_VA_2012_RC1_Instrument.pdf (last visited July 8, 2019).

[40] The attending physician may or may not be employed by the nursing home.

[41] *See* N.Y. State Dep't Health, *Role of the Attending Physician in the Nursing Home*, N.Y. STATE DEP'T HEALTH, https://www.health.ny.gov/professionals/nursing_home_administrator/docs/11-13_att_phys_role.pdf (last visited July 8, 2019).

[42] David Nowels, *Completing and Signing the Death Certificate*, 70 AM. FAM. PHYSICIAN 1813 (2004), *available at* http://www.aafp.org/afp/2004/1101/p1813.html; *see also* Kathryn A. Myers et al., *Improving the Accuracy of Death Certification*, 158 CAN. MED. ASS'N J. 1317, 1318 (1998), *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1229326/pdf/cmaj_158_10_1317.pdf.

[43] Nowels, *supra* note 42.

[44] The standard is codified by each state. When physicians began to refuse to sign death certificates if the deceased person was not their patient for fear of liability, states reacted by lessening the burden to view the corpse.

procedures are supported by customs in the medical field, state statutes, and regulation of the medical field.

A 1993 study indicated that the inaccuracies of reporting the cause of death on death certificates have been problematic and it was confirmed when compared to autopsy results;[45] however, the problem persists and worsens. In 2008, a study addressed physicians and their ability to correctly identify an elderly man's cause of death.[46] Out of 225 physicians, nearly half incorrectly identified the cause and manner of death.[47] A 2010 Florida study produced similar results.[48] There are several noted reasons why a physician inaccurately determines the cause of death and ultimately "checks the wrong box" on a death certificate: a lack of education in forensic sciences, a consensually negative attitude towards death certificates by physicians, and the absence of a requirement for physicians to view the corpse.

1. Lack of Education in Forensic Sciences

One of the main and unique concerns with elder abuse (contrasted to non-elder abuse) is that signs of elder abuse are often similar to symptoms of certain diseases or conditions commonly found in elders.[49] It becomes a problem when "caregivers, Adult

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[45] Myers, *supra* note 42 (discussing the standard in reporting cause of deaths on death certificates).

[46] Chrisun Lee et al., *Gone Without a Case: Suspicious Elder Deaths Rarely Investigated*, PROPUBLICA.ORG (Dec. 21, 2011, 9:00 AM), http://www.propublica.org/article/gone-without-a-case-suspicious-elder-deaths-rarely-investigated (discussing a study which asked physicians to determine the cause of death of an elderly man who had fallen and hit his head and the study concluded of those study participants that correctly identified the primary cause of death as internal bleeding of the brain, nearly two-thirds did not attribute the bleeding to a fall).

[47] *Id.*

[48] *Id.* (discussing study published in 2010 found that nearly half of 371 Florida death certificates surveyed had errors in them).

[49] Catherine C. McNamee et al., *Elder Abuse in the United States*, NAT'L INSTITUTE OF JUSTICE J., Nov. 2006, *available at* http://www.nij.gov/journals/255/pages/elder_abuse.aspx#.

Protective Services agencies,[50] and doctors are often not trained to distinguish between injuries caused by mistreatment and injuries that are the result of accident, illness, or aging."[51] Many advocates argue that those individuals who work with elders should rely on "forensic markers," but those individuals rarely have the training to do so.[52] For example, a forensic marker includes knowing which bruises on an elder individual's body are due to accident and which are due to force.[53] In Larry's case, the funeral director was not trained in forensic science; however, he had seen so many corpses over the course of his career that he was able to recognize that the bruises on Larry's body could not have resulted from accident.[54]

Many people argue for more training in forensic sciences, especially for those physicians who are often required to report causes of death on death certificates.[55] However, it is a common feeling in the medical field that training in this area would be of little value for numerous reasons, the most prominent being the notion that deaths due to elder abuse in the nursing home setting are so rare.[56] This argument is backed by the belief that autopsies of nursing home deaths would not improve the quality of care for those elder individuals.[57] Furthermore, training practicing physicians would require time and money that physicians are not willing to spend on such a "small" problem.[58] Practicing physicians are more concerned with treating and preventing disease than dealing with the already deceased.

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[50] *See* Fla. Dep't. Children & Families, *Adult Protective Services*, MYFLFAMILIES.COM, http://www.dcf.state.fl.us/service-programs/adult-protective-services (last visited July 8, 2019).

[51] McNamee et al., *supra* note 49.

[52] *Id.*

[53] *Id.*

[54] Funeral directors have more knowledge about forensic science than one would think. In many states that have elected coroners, oftentimes a funeral director will be elected to serve as the local coroner. Despite not having as much formal training or education, the funeral directors usually have much more experience.

[55] *Id.*

[56] *Id.*

[57] *Id.*

[58] *Id.*

Due to the stronghold against further training of general or geriatric physicians in forensic science, another remedy may be more appropriate to prevent situations such as Larry's. A common ground between those who support physician training in forensic sciences and those who do not would be to require autopsies. The certifying physician would not be required to have training in forensic science (unless the state or country requires it), and there would be no risk for inaccurate death certificate completion because an autopsy would be performed by an expert in forensic science. This verification system would be the best way to deal with inaccurate cause of death reporting.

By requiring an autopsy after each nursing home death, two different outcomes could result in a certifying physician's work: it could motivate physicians to report accurately on death certificates, so their findings are not constantly overturned, or, it could ensure apathetic physicians continue to report the cause of death inaccurately because there is another party reviewing their work. In either situation, referring elder person deaths to a coroner would alleviate the need to educate physicians in forensic sciences because a coroner—a forensic science expert—would be conducting the autopsy.[59]

2. *Attitude Towards Completing the Death Certificate*

There is a general understanding in the medical world that a large percentage of physicians lack any significant concern for completing medical certifications for death certificates.[60] "The

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[59] Although the autopsy will ensure accuracy in the elder death setting, it still leaves room for error in deaths from younger individuals. Thus, proper training of forensic science to physicians should still be advocated for because accurate reporting of deaths is vital and ethically proper.

[60] Michael Bloor, *A Minor Office: The Variable and Socially Constructed Character of Death Certification in a Scottish City*, 32 J. HEALTH & SOC. BEHAVIOR 273, 281–82 (1991).

completion of death certificates is a very minor office: for most certifying doctors, death certification is an unsupervised, unreported, invisible, and unconsidered activity."[61] Whether inaccuracy in reporting is done intentionally or unintentionally depends on certain circumstances surrounding the death and its registration.

a. Intentional Fraud

A 2010 New York study found that nearly half of the study participants had knowingly reported an inaccurate cause of death.[62] "Of respondents who indicated they reported an inaccurate cause, 76.8% said the system would not accept the correct cause, 40.5% said admitting office personnel instructed them to 'put something else,' and 30.7% said the medical examiner instructed them to do so."[63] These are very disturbing figures considering the importance of death records in each populace. Causes of death tell an important story about a community—it speaks to its wellness and its ability to care for its citizens. A physician purposely entering the incorrect cause of death into the Electronic Death Registration System because it would not allow the correct entry speaks volumes to the efficiency, or lack thereof, of computer systems that assist with this role in completing death certificates.[64] Even though a certifying physician is required by state law to enter the cause of death in "the physician's best medical opinion,"[65] this intentional failure to correctly enter the cause of death continues.[66]

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[61] *Id.*

[62] Barbara A. Wexelman et al., *Survey of New York City Resident Physicians on Cause-of-Death Reporting, 2010*, 10 PREVENTING CHRONIC DISEASE, May 9, 2013, at 1, *available at* http://www.cdc.gov/pcd/issues/2013/12_0288.htm.

[63] *Id.*

[64] *Id.* On the other hand, France has had a positive reaction to electronic filing. Their accuracy of death certificates has improved since their implementation of electronic death registration. *See* Delphine Lefeuvre et al., *Quality Comparison of Electronic Versus Paper Death Certificates in France,* POPULATION HEALTH METRICS, Feb. 17, 2014, *available at* https://www.ncbi.nlm.nih.gov/pubmed/24533639.

[65] Bureau of Vital Statistics, *supra* note 18.

[66] Wexelman et al., *supra* note 63.

Although uncommon, there is evidence to suggest that some physicians will go so far as to ignore subtle signs of abuse because it may adversely impact the family.[67] Some physicians may ignore clear signs of abuse to avoid troubling the surviving family members any further. For example, if Larry's family was extremely distraught over his death, the physician may have reported the cause of death as "natural causes" despite signs of abuse to protect the family from further suffering. He could have seen unusual bruising and scabs on Larry's hip, but because he was concerned with the family's emotional well-being, he ignored tell-tale signs of abuse. Protecting the family's feelings should not excuse the intentional failure to report valid suspicions of abuse.

According to most states' laws, if abuse is suspected by the physician of the deceased, the proper authorities must investigate and an autopsy must be performed.[68] Because the physician is an individual mandated by statute to report abuse, the failure to do so has criminal repercussions. Requesting an autopsy may also become an issue if the decedent's or family's religion forbids post-mortem examination.[69] Some states have a statutory waiver of autopsy if the decedent had a written religious objection.[70]

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[67] Leslie S. Libow et al., *The Autopsy and the Elderly Patient in the Hospital and the Nursing Home: Enhancing the Quality of Life*, 63 GERIATRICS, Dec. 2008, at 12, 14, *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2920045//.

[68] Lori Stiegel & Ellen Klem, *Reporting Requirements: Provisions and Citations in Adult Protective Services Laws, by State,* ABA COMMISSION LAW & AGING, http://www.americanbar.org/content/dam/aba/administrative/law_aging/MandatoryReportingProvisionsChart.authcheckdam.pdf (last visited July 8, 2019).

[69] *See* Memorandum from Stephen McArthur, then law student, to Agudath Israel of Am. Legal Support Servs., *Summary of Autopsy Consent Laws* (Apr. 27, 2007), *available at* http://legalsupportservicesllc.org/wp-content/uploads/2014/03/Autopsy-Laws-Around-the-US-and-Religious-Accomodation.pdf

[70] *Id.*

b. Unintentional Fraud

Death certificate accuracy is frustrated more so when physicians are not concerned with accurate cause of death reporting for elder individuals. Many physicians do not understand the general importance of cause of death reporting. Particularly with elderly individuals, some physicians will find that the elder person died of "natural causes," but what the physician truly believes is that the elder person died of "old age."[71] The physician, and most of society, think that when an elder person dies, he or she had "lived a long life" and it was "their time to go." This ageist response is one of the main reasons that autopsies are rarely performed on elder persons.[72] Despite any truth underlying this ageist mindset, there should still be a seriousness in determining the proper cause of death.[73]

In the case of a nursing home death, the cause of death is extremely important considering the frequency and ease to abuse elders living in these facilities. It is essential to know how people who reside in nursing homes die in order to determine the quality of care in that facility. If the cause of death is consistently being inaccurately reported, it is nearly impossible to properly determine the facility's quality of care and if its staff has committed any foul play. For example, if several nursing home patients at Sunny Oaks had died of sepsis, then this should raise serious red flags as to the quality of care at that nursing home. Additional measures to prevent or avoid inaccurate reporting on death certificates can help to accurately determine which nursing homes house abusers.

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[71] Libow et al., *supra* note 67, at 15.

[72] *See infra* pt. IV(A).

[73] *See* Russell G. Thornton, *Death Certificates*, 19 BAYLOR U. MED. CTR. PROCEEDINGS 285, 285 (2006), *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1484541/; *see also* Carol McAllum et al., *Death Certification and Doctors' Dilemmas: A Qualitative Study of GPs' Perspectives*, 55 BRIT. J. GEN. PRAC. 677, 677 (2005), *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1464060/ (determining the cause of death is important for other reasons, including: community statistic reporting, future scientific research, evidence in wrongful death lawsuits, the settlement of estates, and the promotion of future health planning).

3. Physicians Are Not Required to View the Corpse

When Larry's body arrived at the funeral home, the funeral director immediately noticed the bruises. The funeral director knew that the death certificate stated "natural causes" but he did not find anything "natural" about these bruises. The question then surfaces—how did the certifying physician not notice these bruises when indicating the cause of death? In this instance, the certifying physician did not actually view Larry's body. "In many states, laws are so lax that doctors can sign off on death certificates without having seen a patient in months or actually viewing the body."[74] In Florida, a physician can mark the cause of death without having seen his or her patient within twelve months of the day of death.[75] Therefore, it was legal and ethical for Larry's physician at Sunny Oaks to mark the cause of death as "natural" despite not having seen him for two weeks.[76] It is unsettling that Larry's abusers may have gotten away with his death even though the signs were clearly visible on his body.

If no doctor is required to have treated or visited the patient within a year of the death, and no doctor is required to view the body after death, then how are physicians able to accurately determine a cause of death, let alone catch signs of abuse? It is a conundrum that the person most relied on to determine a cause of death is not even required to view the corpse.[77] At the time of death, the certifying physician is in the best position to determine whether a deceased

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[74] Lee et al., *supra* note 46.

[75] FLA. STAT. § 382.008(3); Bureau of Vital Statistics, *supra* note 18.

[76] *See* FLA. STAT. § 382.008(3); Bureau of Vital Statistics, *supra* note 18.

[77] *See* FLA. STAT. § 382.008(3); Bureau of Vital Statistics, *supra* note 18.

person had been abused.[78] For example, if Larry's physician had actually viewed Larry's corpse, he would have been able to clearly see the bruising and further question the cause of death. Therefore, at the very least, laws should require the certifying physicians in nursing homes to actually view the body, no matter how long ago the doctor had last seen his or her patient.[79] Further, if states are hesitant to put more pressure on physicians by raising the standard for cause of death completion on death certificates, then there should be some protective measure for more vulnerable individuals, such as nursing home residents. At the very least, states should require the certifying physician (not necessarily the attending physician) to actually view the corpse before determining the cause of death. It is unreasonable to allow elders, like Larry, to slip through the cracks because no one actually examined his body.

One of the main reasons lawmakers allow physicians to sign off on death certificates without ever seeing the corpse is due to fear of excessive physician liability.[80] Physicians were initially reluctant to sign off on a person's death if they had not recently seen or treated the person or had no involvement with the person's death. Due to this fear, and delays to families in retrieving death certificates, legislatures passed laws that would make certifying physicians feel more comfortable with signing off on a death certificate.[81] This includes the Florida twelve-month rule as well as laws that permit "any person that in good faith provides information required by this article shall not be subject to criminal prosecution or any action for

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[78] This is in states where an autopsy is not required after a nursing home death. If an autopsy is required, then the coroner is in the best position to determine whether abuse occurred to a deceased person, leaving the certifying physician in the second-best position.

[79] In some circumstances, nurses and other persons trained in some variation of the medical field may mark the time and cause of death if the attending physician is not available. *See* Bureau of Vital Statistics, s*upra* note 17.

[80] Jeb Phillips, *Coroner Says Office Burdened Because Doctors Won't Sign Death Certificates*, COLUMBUS DISPATCH (Feb. 4, 2013 12:01 AM), http://www.dispatch.com/content/stories/local/2013/02/04/cause-of-death-hard-to-reach.html.

[81] *Id.*

damages."[82] In Australia, the person who may conduct an autopsy is "the medical practitioner who was either responsible for the deceased person's medical care during their last illness or immediately before death, or who examined the body of the deceased person after death . . . provided the medical practitioner is 'comfortably satisfied' as to the cause of the death and no other circumstances are present which require the death to be reported to the Coroner."[83] With this flexible rule, one may wonder how a physician can provide adequate medical certification and relevant information in "good faith" without having seen the corpse.

Additionally, nursing home deaths are very different from other deaths, such as deaths resulting from accidents, diseases, or suicide. People in nursing homes are typically mentally and physically infirm and are under constant medical care. The residents of nursing homes are required by law to be seen by a doctor every 30 days for the first 90 days and then once every 60 days thereafter.[84] There is a reason that individuals living in nursing homes must be seen so frequently; their bodies are fragile and more susceptible to injury than younger persons. For example, Larry's attending physician did not know that Larry actually died from severe dehydration, pneumonia, and sepsis because it took only a week to transpire. Laws that permit physicians to sign death certificates after not seeing the body do not translate well with the elder population. Therefore, not only is viewing the corpse necessary for elder persons, it is even more necessary for nursing home residents due to the increased risk of abuse.

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[82] *E.g.* W.V. STAT. § 16-5-31 (2019); *see also* Jim Kaplan, *When Your Patient Dies: Death Certificate Responsibilities Under West Virginia Law,* 11 W. VA. BOARD OF MED. Q. NEWSL., Jan.–Feb. 2010, at 8.

[83] Sara Bird, *How to Complete a Death Certificate: A Guide for GPs*, 40 AUSTL. FAM. PHYSICIAN 446, 447 (2011), *available at* http://www.racgp.org.au/download/documents/AFP/2011/June/201106bird.pdf.

[84] 42 C.F.R § 483.30(c) (2019) (This time frame requirement will vary amongst the states.).

C. Physician Conflict of Interest and Liability

Nearly every medical school in the United States requires their graduates to recite the Hippocratic Oath.[85] Although the Oath has been reworked over the years to conform to modern medicine, it still upholds the traditional values required of doctors: "treat the sick to the best of one's ability, preserve patient privacy, teach the secrets of medicine to the next generation, and so on."[86] However, there are instances in which the Hippocratic Oath is twisted or forgotten for a physician's own personal agenda. Physicians employed by nursing homes may find themselves in a sticky situation when they suspect a death is caused by abuse but are personally conflicted with reporting it. Their credibility is compromised because they are employed for the very entity that may be responsible for its residents' abuse. Also, physicians may not feel obligated to report the crime because their license is not at stake in certain circumstances.

As previously mentioned, physicians, amongst other healthcare professionals, are necessary for proper nursing home treatment and care.[87] Attending physicians who treat nursing home residents may be either employed by the nursing home or contracted to visit certain patients.[88] Moreover, each nursing home is required to have a medical director, whose duties include implementing resident care policies and coordinating the medical care in the facility.[89] However, potential conflicts of interest between a doctor and his or her patient is a concern because there is also a relationship between the employee (attending physician) and the employer

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[85] Peter Tyson, *The Hippocratic Oath Today*, PBS NOVA (Mar. 27, 2001), http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html.

[86] *Id.*

[87] *See* Soc'y for Post-Acute & Long-Term Care Medicine, *Role of the Attending Physician in the Nursing Home*, POSITION STATEMENT, SOC'Y FOR POST-ACUTE & LONG-TERM CARE MEDICINE (Mar. 1, 2003), http://www.paltc.org/amda-white-papers-and-resolution-position-statements/role-attending-physician-nursing-home.

[88] 42 C.F.R. § 483.70(f) (2019).

[89] 42 C.F.R. § 483.70(h).

(nursing home facility).[90] Although there are moral and legal standards that physicians are required to uphold, the physician may have a disincentive to report suspected abuse by its employer. Because the physician is paid by the nursing home, it would be rationally unsound (but ethically sound) for the physician to "tattle" on the nursing home that signs his paycheck each month. For example, Larry's physician might not have reported the crime even though she knew he was being neglected because it would trigger an investigation involving the nursing home. An investigation would reflect poorly on the nursing home and the physician may not want to deal with the scrutiny that would follow.

Moreover, more states are allowing nursing homes to employ physicians, but there is a reluctance to do so.[91] This reluctance is primarily focused on the idea that physicians should not be concerned with corporate profits, nor should an entity be able to interfere with a physician's practice of medicine.[92] Physicians working in-house for nursing homes have two duties: providing care and treatment for their patients and providing profit and a "good name" for the nursing home. Despite the potential conflict, most states understand the benefits of having in-house physicians, such as having the doctor available in the facility, improved efficiency in providing medical services, greater expertise in elder care, and more consistent medical services.[93]

If a physician fails to report the cause of death within the state's statutory time frame, then some states require the physician

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[90] *Governor Signs New Law Allowing Nursing Homes to Employ Physicians in Washington* (May 9, 2011), *available at* https://www.jdsupra.com/legalnews/governor-signs-new-law-allowing-nursing-27404/.

[91] *Id.*

[92] *Id.*

[93] *Id.*

to be reported to their state's medical board for review.[94] Moreover, if a physician knowingly and intentionally signs a cause of death incorrectly, he or she should also be reported to their state's medical board.[95] However, in the nursing home setting, if a physician makes a mistake regarding a patient's care, there is almost no liability on the physician's part.[96] For example, if a physician inaccurately prescribes medication, the nursing home may be cited for the error, but more than likely, the prescribing physician will not incur any consequences.[97] The physician's error is ignored, and instead, all the consequences are focused on the nursing home.[98]

III. LAWS OF THE UNITED STATES FOR PREVENTING NURSING HOME ABUSE

Every state has passed various laws to address the growing concern of abuse in nursing homes.[99] This Section will discuss the various laws that have been enacted as an attempt to curtail the prevalence of nursing home abuse. Moreover, this Section will discuss the benefits of each of these laws, and why they would be best supplemented with laws in Arkansas that require autopsies of all nursing home deaths.

A. Reporting Laws

As of 2015, almost every state in the United States had mandatory reporting laws of elder abuse.[100] The only exception was

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[94] GA. STAT. §§ 31-10-15, 43-34-8 (2019).

[95] *See, e.g.*, FLA. STAT. § 458.331 (2018).

[96] Sam Roe, *Nursing Home Doctors Untouched Even as Facilities Are Cited*, CHI. TRIB., Oct. 28, 2009, *available at* http://www.chicagotribune.com/lifestyles/health/chi-nursing-home-doctors-oct28-story.html.

[97] *Id.*

[98] *Id.*

[99] *See generally* Univ. Minn., *NH Regulations Plus*, UNIV. MINN., http://www.hpm.umn.edu/nhregsplus/NHRegs_by_State/By%20State%20Main.html (last updated Mar. 19, 2012) (offering a state-by-state guideline of the different rules and regulations of nursing homes).

[100] Stiegel & Klem, *supra* note 68.

New York.[101] Some countries, such as the United Kingdom and Australia, have no mandatory reporting of elder abuse.[102] Mandatory reporting statutes generally state that certain persons are required to report to the appropriate authorities that they have knowledge or suspicions of abuse of a vulnerable adult.[103] In Florida, the persons required to report include physicians, guardians, social workers, pharmacists, or even a bank employee.[104] In other words, it is the person or persons in the best position to know of the abuse. In most states, the statute does not require the reporting person to have actual knowledge of the abuse; the person may simply have "reasonable cause to suspect" that abuse has occurred or is occurring.[105] In order to encourage persons hesitant to report abuse, the reporter of the abuse will remain anonymous.[106] If a person knows of any abuse of a vulnerable adult occurring and fails to report it, that person would be committing a crime in most states.[107]

However, prosecuting an elder abuse case can be daunting for several reasons. First, there is lack of training and education of prosecutors in complex medical and financial issues involving elders. Also, an elderly victim may not be a credible victim due to mental infirmities and related mental illnesses.[108] Thus, not only is it hard to prosecute an abuser of vulnerable adults, but it is much more difficult to prosecute those who simply had knowledge of the

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[101] Ryan P. Baker et al., *New York State Doesn't Have Mandatory Reporting: Good or Something to Change?*, NYC ELDER ABUSE CTR., http://nyceac.com/elder-justice-dispatch-new-york-state-doesnt-have-mandatory-reporting-good-or-something-to-change/ (Jan. 8, 2015).

[102] AMANDA PHELAN, INTERNATIONAL PERSPECTIVES ON ELDER ABUSE 40, 194 (2013); *see also* Austl. Legal Info. Inst., *Commonwealth of Australia Consolidated Acts,* AUSTL. LEGAL INFO. INST., http://www.austlii.edu.au/au/legis/cth/consol_act/aca199757/s63.1aa.html (last visited July 8, 2019) (Australia has only recently passed a 2007 amendment requiring Aged Care providers to report abuse.).

[103] *See, e.g.*, FLA. STAT. § 415.1034 (2019).

[104] *Id.*

[105] *Id.*

[106] FLA. STAT. § 415.107 (2019).

[107] FLA. STAT. § 415.111 (2019).

[108] Elisia Gatman Kupris, *Protection of Our Elderly: A Multidisciplinary Collaborative Solution for Alaska*, 30 ALASKA L. REV. 47, 54 (2013).

abuse and did not report it. For example, if a nursing home staff member knew that his or her coworker was abusing Larry and said nothing, he or she would be committing a crime in most states. An employee may decide not to report suspected abuse, perhaps because he or she is friends with the abusing coworker or because he or she believes it is "none of his or her business."

B. Nursing Home Staff Requirements: Training, Background Checks, and Education

Nursing home staff training and education requirements are determined by state and federal law. For the nursing homes to qualify for Medicaid and Medicare programs, they must meet federal standards. The federal regulations require nursing homes to have sufficient staff,[109] develop a comprehensive care plan for each resident,[110] promote each resident's quality of life,[111] and maintain accurate, complete, and easily accessible clinical records on each resident.[112] In addition to these federal standards, many states have expanded laws regarding nursing homes.[113]

As the population ages, there is a growing need for more nursing home staff. Federal law provides a vague requirement that nursing homes must have sufficient staff to "maintain the highest practicable physical, mental, and psychosocial well-being of its residents."[114] States may impose stricter standards as to staffing requirements.[115] Many states may also require each nursing facility to have written policies and procedures that address staff education,

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[109] 42 C.F.R. § 483.35 (2019).

[110] 42 C.F.R. § 483.20(b) (2019).

[111] 42 C.F.R. § 483.24 (2019).

[112] 42 C.F.R. § 483.70(i)(1).

[113] *See generally* Charlene Harrington et al., *Nursing Home Staffing Standards in State Statutes and Regulations*, NAT'L LONG-TERM CARE OMBUDSMAN RES. CTR. (Jan. 4, 2017), http://ltcombudsman.org/uploads/files/support/Harrington-state-staffing-table-2010_%281%29.pdf.

[114] 42 U.S.C. § 1395i-3(b)(2) (2012).

[115] Harrington et al., *supra* note 113.

including HIV/AIDS training.[116] While nurses and doctors master high levels of education and training, most other aides employed by nursing homes have no formal education and receive minimal training.[117] These aides spend the most time caring for nursing home residents and are the persons most often to deal with the demands and aggression of dementia patients.

Many other countries do not have mandatory staffing ratios in nursing home settings. Across Australia, there are no mandated requirements for nursing home staff to resident ratios. More specifically, the Aged Care Act of 1997 states only that there must be "an adequate number of appropriately trained staff."[118] Considering no other regulations or laws have been passed in other Australian states, this standard is very lax and broad. Therefore, for Australian aged-care homes to receive government subsidies, they must simply have "an adequate" number of staff.[119] Moreover, the staff must be "appropriately" trained.[120] This does not require registered nurses or other geriatric trained healthcare professionals.

Nearly 25% percent of nursing home staff who have been prosecuted for elder abuse had a criminal background.[121] Requiring background checks would prevent staff with criminal backgrounds from working with vulnerable populations. "Because these

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[116] Fla. Admin. Code 59A-4.106(4)(f) (2015).

[117] Yoshiko Yamada, *Profile of Home Care Aides, Nursing Home Aides, and Hospital Aides: Historical Changes and Data Recommendations*, 42 GERONTOLOGIST 199, 200–01 (2002), *available at* http://gerontologist.oxfordjournals.org/content/42/2/199.full.pdf.

[118] *Aged Care Act* 1997 (Cth) pt. 4.1, div. 54, § 54-1, *available at* https://www.legislation.gov.au/Details/C2008C00075/Html/Text#param26.

[119] *Id.*

[120] *Id.*

[121] Jennifer Marciano, *Mandatory Criminal Background Checks of Those Caring for Elders: Preventing and Eliminating Abuse in Nursing Homes*, 9 ELDER L.J. 203, 204 (2001) (there is a debate between an individual's right to privacy, as a nursing home resident or employee, and a contractual right to monitor loved ones with everyone's consent beforehand. In some states, such as Florida, there is a stronghold against electronic monitoring and that all parties being recorded must have notice or consent to the recording beforehand.).

individuals are the ones caring for the patients on an around-the-clock basis, it is important that those hired to work in such facilities are fit for the job."[122] For example, the aides attending to Larry could have become increasingly frustrated with him to the point where they were physically abusing him without really understanding their actions. If these aides had the proper training for dementia patients, they would be better equipped on how to best handle a dementia patient's aggression and hostility without resorting to physical abuse.

More recently, jurisdictions have begun to adopt electronic monitoring statutes in order to record inside the rooms of nursing home residents.[123] Texas was the first state to enact such legislation, and it has proven to be a success thus far.[124] The statute requires that the nursing home, its residents, and its staff be notified of the electronic monitoring.[125] One of the great benefits of such a statute is it deters abuse because the staff are fully aware that they are being recorded. However, due to potential ethical and privacy concerns, there is an ongoing debate over whether nursing home surveillance cameras are a viable option.[126]

IV. AUTOPSIES AS THE CATCH-ALL LAW OF NURSING HOME ABUSE

This Section will discuss the lack of autopsies currently being performed on elder decedents due to an ageist bias. This Section will also report the need for autopsies after a nursing home death and why other laws preventing abuse are insufficient.

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[122] *Id.* at 212.

[123] As of 2015, only five states have passed statutes permitting electronic monitoring in nursing homes. 210 ILL. COMP. STAT. § 32 (2016); WASH. REV. CODE. § 388-97-0400 (2008); OKLA. STAT. TIT. 63, § 63-1-1953.5 (2017); N.M. STAT. ANN. § 24-26 (2004); TEX. STAT. §§ 242.841–242.852 (2015).

[124] TEX. STAT. §§ 242.841–242.852.

[125] *Id.*

[126] Katherine Anne Meier, *Removing the Menacing Specter of Elder Abuse in Nursing Homes Through Video Surveillance*, 50 GONZ. L. REV. 29 (2014).

A. Ageism and Autopsies

If a physician believes that a death is unusual, or there are signs of foul play, the death must be reported to the coroner for further investigation.[127] In most states, autopsies (or some type of investigation) are required when there is a suicide, death of a child, death of an inmate, suspicion of foul-play, and more.[128] The purpose of these autopsy and investigation requirements is to determine whether a crime has been committed. For example, when there is a death of a child, an autopsy is legally required because the death of a child is such a preternatural occurrence. However, on the other end of the age spectrum, an elder person dying is not unusual at all; it is expected.

Nursing home deaths are rarely reported to a coroner for an autopsy.[129] In the United States between 1972 to 2007, the percentage of autopsied deaths had declined more than 50%.[130] The older the person's age at death, the less likely an autopsy will be performed.[131] For persons aged 15–24, the autopsy rate is 60%; for persons aged over 65, the autopsy rate is less than 5%.[132] This is a drastic difference for something as discriminatory as a decedent's age. In Sweden, researchers sought to explain the country-wide decline in performed autopsies.[133] The study noted that "patients

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[127] *See* Chrisun Lee et al., *Gone Without a Case: Suspicious Elder Deaths Rarely Investigated*, PROPUBLICA (Dec. 21, 2001, 9:00 AM), http://www.propublica.org/article/gone-without-a-case-suspicious-elder-deaths-rarely-investigated. The article discusses a study that asked a group of physicians to determine the cause of death of an elderly man who had fallen and hit his head. *Id.* Of those study participants who correctly identified the primary cause of death as internal bleeding of the brain, nearly two-thirds of those persons did not attribute the bleeding to a fall. *Id.*

[128] *E.g.* FLA. STAT. § 406.11(1)(a) (2019).

[129] Libow et al., *supra* note 67.

[130] Donna L. Hoyert, *The Changing Profile of Autopsied Deaths in the United States, 1972–2000*, 65 NCHS DATA BRIEFS (Hyattsville, MD), Aug. 2011, at 1, 1, *available at* https://www.cdc.gov/nchs/data/databriefs/db67.pdf.

[131] *Id.*

[132] *Id.*

[133] P. Lindström et al., *Declining Autopsy Rate in Sweden: A Study of Causes and Consequences in*

who died in nursing homes were less often sent for a post mortem examination than were patients who died at the hospital," despite the percentage of people dying in nursing homes increasing from 1% to 29%.[134]

Law makers need to consider this age bias. Physicians swear to help those who are sick, but their duties must extend beyond their patient's last breath. A physician's duty should last until accurate completion of the medical certification for death certificate purposes. Physicians should be held to a higher standard when reporting a cause of death, despite any mitigating factors that would deter them from doing so.

B. Autopsy Requirement for Cause of Death Accuracy

As discussed in Part II(B), autopsies have been used to prove the inaccuracies of causes of death listed on death certificates. Most states require specific training for the people conducting autopsies.[135] For example, a medical examiner must be licensed according to state law, receive periodic training, and submit to periodic audits.[136] However, in Georgia, coroners are elected officials by probate judges.[137] The lack of uniformity between the states on training in forensic science could be a contributing factor for inaccuracies in death certificate reporting. Moreover, there is a lack of training of post mortem examination for new physicians.[138]

Malmö, Sweden, 242 J. INTERNAL MED. 157, 157 (2003), *available at* http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2796.1997.00178.x/full.

[134] *Id.*

[135] Ctr. Disease Control & Prevention, *Coroner Training Requirements*, CDC, http://www.cdc.gov/phlp/publications/coroner/training.html (last updated Jan. 15, 2015) (discussing a state by state guide for training requirements of coroners); *see also* Sandra Bartlett, *Coroners Don't Need Degrees to Determine Death,* NPR (Feb. 2, 2011, 12:06 PM ET), http://www.npr.org/2011/02/02/133403760/coroners-dont-need-degrees-to-determine-death.

[136] Fed. Motor Carrier Safety Admin., *National Registry of Certified Medical Examiners: Medical Examiners & Assistants*, U.S. DEPT. TRANS., https://nationalregistry.fmcsa.dot.gov/NRPublicUI/MedExAssist.seam (last updated May 30, 2019).

[137] GA. STAT. §§ 45-16-1(a), 45-16-2(a) (2019).

[138] Mindy J. Hull et al., *Resident Physician Opinions on Autopsy Importance and Procurement*, 38 HUMAN PATHOLOGY, Feb. 2007, at 342, 342, *available at*

Despite the decline in rates of autopsy performance, it is shown that new medical residents actually desire to learn how to properly perform autopsies.[139] They understand the value that autopsies bring, not only in medical education, but also in new medical research.[140]

Australia is one of the few countries that requires any death occurring in Supported Residential Facilities[141] be reported to the coroner.[142] Although the death is reported to the coroner, he or she makes the ultimate decision whether to perform an autopsy. While this is a step in the right direction, it is not entirely sufficient. Coroners would be conducting a visual, external inspection of the deceased elder, and as discussed above, elder abuse is more difficult to discover from an external viewing.

Autopsies are the most accurate way to determine a person's cause of death. Despite the numerous types of laws enacted to prevent abuse, none are particularly helpful when trying to determine if a death was *caused by* abuse; rather, these laws are excellent attempts to prevent and deter abuse. States that decide to follow in Arkansas's path and require autopsies of all nursing home deaths will most likely find more variation in the causes of death listed. Instead of the biased physician putting "natural causes" as the manner of death, an autopsy report will give an unbiased and uncompromised assessment as to the actual cause of death. Furthermore, Arkansas's law is not limited to persons who die in nursing homes, it also extends to persons who die within five days

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http://www.humanpathol.com/article/S0046-8177(06)00508-9/fulltext?cc=y=.

[139] *Id.*

[140] *Id.*

[141] This is the American equivalent to nursing homes, assisted living facilities, and skilled-nursing homes.

[142] *See Supported Residential Facilities Act* 1992 (SA), *available at* https://www.legislation.sa.gov.au/LZ/C/A/SUPPORTED%20RESIDENTIAL%20FACILITIES%20ACT%201992.aspx; Bird, *supra* note 82.

of leaving a nursing home,[143] which ensures that any possibility of abuse is detected. Requiring autopsies is the most efficient way to address deaths caused by nursing home abuse and impose the appropriate punishment.

V. CONCLUSION

When death is viewed as an imminent and natural event for an elder person, how do we monitor instances of unnatural deaths? In the nursing home context, certifying physicians have proved to be unreliable in this area; therefore, the best solution is for an autopsy requirement. "The autopsy is the ultimate 'peer review.'"[144] "The autopsy is objective; it is the gold standard for quality assessment of medical care."[145] Several reasons for not performing an autopsy, including those mentioned in part II(B)–(D), are extra hospital costs, excessive reliance on lab results and imaging tests, and fear of litigation.[146] However, the need for abuse prevention and punishment outweighs any costs or physician concerns.[147] The scenario of Larry is all too real for some families, and it is preventable. Making an autopsy a requirement for all nursing home deaths promises accuracy in determining an elder individual's cause of death and ensures that nursing homes are properly combatting abuse. Therefore, all states should require nursing homes to report deaths that occur onsite to the coroner for examination.

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[143] ARK. STAT. § 12-12-1709(a)(3)(A).

[144] Libow et al., *supra* note 67.

[145] Keyvan Ravakhah, *Death Certificates Are Not Reliable: Revivification of the Autopsy*, 99 S. MED. J. 728, 729 (2006).

[146] Libow et al., *supra* note 67, at 14 tbl.1.

[147] Dean Olsen, *Not All Nursing Home Deaths Receive Scrutiny*, STATE J.-REG. (Springfield, Ill.), Dec. 8, 2008, 7:05 AM CST, *available at* http://www.sj-r.com/article/20081208/News/312089877/?Start=1.

THERE'S NO PLACE LIKE A HOME . . . OR A NURSING HOME THAT LOOKS LIKE HOME[1]

A VISIT TO DE HOGEWEYK[2]

By
Rebecca C. Morgan[3]
Joshua Castro
Jose German Garcia
Brittany T. Gibson
Sammy Hall
Elizabeth Hauber
Amika Jeffries
Jenna C. Jordan
Christina Morelli
Ambree Muller
Lauren Riedy
Nola Seekie
Sarah Speicher
Hannah M. Yoder

I. INTRODUCTION

Stetson University College of Law offers several summer study abroad programs for Stetson's law students as well as students from other law schools who are part of Stetson's consortium of law schools for such programs. One of the summer programs is a month-long course held in The Hague. For the past several years, one week of the course has been devoted to the topic of elder law. During the 2017 program, students in one section of the program were given an

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[1] © 2019. All rights reserved.

[2] De Hogeweyk, https://hogeweyk.dementiavillage.com/en/ (last visited Sept. 22, 2019).

[3] Professor of Law and Boston Asset Management Chair in Elder Law, Center for Excellence in Elder Law, Stetson University College of Law. My co-authors were students in Stetson's Summer Abroad Program during July of 2017 and toured De Hogeweyk with me.

opportunity to take an afternoon field trip to De Hogeweyk.[4] In the United States, De Hogeweyk is sometimes popularly referred to as the "Dementia Village," but as we learned on our field trip, the better title for it is "the Neighborhood." Twenty students attended this field trip and as a condition of participation, agreed to write a paper detailing their observations.[5]

This article will look generally at the historical nursing home model in the United States, discuss a few innovations in nursing home models in the United States, and describe De Hogeweyk's model as we learned about it during the tour. Mainly, however, this article will share the students' expectations, personal observations, and conclusions drawn from their visit.[6]

II. THE TYPICAL AMERICAN NURSING HOME MODEL

This article is not about the history of nursing homes in the United States. However, to put the students' observations in perspective, and for comparison purposes, one needs to think about the traditional model of American nursing homes. When nursing homes specifically started to develop—at least in the model we think of today— Bruce Vladeck points out while discussing the development of nursing homes, policies, and regulations that

> [i]n the early stages of their development, the problem was defined as one of income poverty for the elderly and especially of the persistence of public almshouses, the heirs to the tradition of in-door relief dating back to Elizabethan times. Since World War II, the problem has been defined as one of support for, and then regulation of, general acute care

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[4] De Hogeweyk, *supra* note 2.

[5] Fourteen of the twenty students completed the assignment.

[6] The purpose of this article is not to cover the modern nursing home in the United States but instead to share the students' experiences in their own words.

> hospitals, and more broadly, of the health care needs of the elderly.[7]

The growth in nursing homes to where they are today was somewhat encouraged by the demographics and policies of our country: "the growth of the frail elderly population, many of whom had limited resources . . . [and] public policy designed to minimize the use of acute hospitals . . . ."[8]

There are two variations when we think of American nursing homes: whether the facility is a non-profit or a for-profit.[9] For-profit nursing homes are more common in the United States than non-profit ones.[10] The for-profit model proliferated in the United States for various reasons, including Medicaid's coverage of long-term, custodial nursing home care and Medicare's limited coverage of skilled nursing home care.[11] Policy, of course, shaped how the nursing home industry developed in the United States. As Vladeck explains it in discussing the history of nursing home public policy in the United States:

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[7] BRUCE C. VLADECK, UNLOVING CARE: THE NURSING HOME TRAGEDY 32 (1980).

[8] Monsignor Charles J. Fahey, *Culture Change in Long-Term Care Facilities: Changing the Facility or Changing the System?*, *in* 2 J. SOC. WORK LONG-TERM CARE 35, 40 (2003) and CULTURE CHANGE IN LONG-TERM CARE 35, 40 (Audrey S. Weiner & Judah L. Ronch eds., 2003).

[9] VLADECK, *supra* note 7, at 8. "The existing nursing home industry is almost entirely a creation of public policy. Two-thirds of the total revenue of nursing homes comes from government. The explosive growth in the number and capacity of nursing homes over the past fifteen years was prompted primarily by the increased availability of public funds." *Id.* at 4*; see also id.* at 8 (noting as part of the physical differences between nursing homes and hospitals that most of the nursing homes are for-profit, and discussing the physical plant of the for-profit facilities and comparing those to the physical layout and design of the non-profit ones).

[10] *Id.* at 8–9 (noting (at the time the book was published) that "[a]bout three quarters of all nursing homes are proprietary. Between 5 and 10 percent are operated directly by government. The remaining 3,000 or so are operated by charitable organizations, most commonly those under religious or denominational auspices.") (citations omitted).

[11] For a history of nursing homes generally, see *id.*, especially pages 33–38 (discussing poor houses, the changes as a result of Social Security with the law's restrictions on using "old age assistance" funds for "any 'inmate of a public institution'" (that is a poor house), and then the gradual development of for-profit homes).

> The history of public policy toward nursing homes is largely a byproduct of broader social welfare legislation, but in a tangential fashion. Recounting that history is like describing the opening of the American West from the perspective of the mules; they were certainly there, and the epochal events were certainly critical to the mules, but hardly anyone was paying very much attention to them at the time.[12]

The typical U.S. nursing home model until recently was based on a medical model, copying the layout of a hospital floor.[13] There is a hallway from which doors open directly into the patient rooms. The hallways are like spokes emanating from the wheel, where the nurses' station, command central, is located.[14] There are key differences between patients in hospitals and residents of nursing homes[15]—this is an important point when considering that U.S. nursing homes adopted a medical model of design yet are designed to serve residents who have differing health issues and abilities than patients in hospitals.[16]

Another author described the U.S. nursing home model this way:

> "[t]he predominantly private nursing home industry that we see in the United States today is a late twentieth-century phenomenon. The industry is a product of increased life expectancy[,] . . . a result of increasing geographical mobility, the changing

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[12] *Id.* at 31.

[13] *Id.* at 7 (describing the nursing home's similarities to a hospital, including the patient floor hallway, doors, rooms, furniture, and location of the nurses' station).

[14] *Id.*

[15] *Id.* at 7–8 (explaining that "while the most important differences are in the characteristics of their patients and their staff and in what patients and staff do all day, there are also physical differences" between the facilities).

[16] *Id.*

> nature of the extended family, and changing patterns of care."[17]

This is compared to the prior century's care model where elders were mainly taken care of in their homes.[18] The shift to the private model of nursing homes seemed to occur primarily after World War II, with a significant impetus coming in 1965 when Medicare and Medicaid programs were adopted.[19] According to one statistic prior to that time, there were about a quarter of a million nursing homes in the United States compared to one million by about 1970.[20] As well by 1970, there was also a marked shift from the "mom and pop" style of nursing home to the corporate model[21] we see prevalent today.[22] By the mid-1980s, according to one source, a proliferation of corporate-owned chains of nursing homes existed in the United States.[23] These corporate-owned nursing homes became a specific type: "regimented, standardized, institutionalized, . . . and devoid of a warm, homelike atmosphere."[24] The same author went on to describe his perception of nursing homes:

> Many of them have explicitly panoptic designs—nurses' stations are hubs from which radiate wings of rooms. The corridors of each wing and the front rooms of each—usually public areas such as activities rooms, TV and dining rooms—can be

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[17] John Braithwaite, *The Nursing Home Industry*, 18 CRIME & JUST. 11, 18 (1993).

[18] *Id.*

[19] *Id.*

[20] *Id.* (citing VLADECK, *supra* note 7, at 103).

[21] *Id.* at 19.

[22] *See, e.g.*, Kieran Walshe, *Regulating U.S. Nursing Homes: Are We Learning from Experience?* 20 HEALTH AFF. 128, 132 (2001) ("Over the past decade the nursing home industry has become increasingly dominated by major corporations, the largest of which control hundreds of nursing homes and many thousands of beds. This trend may reflect the economics of nursing home provision but also may have been accelerated by nursing home regulation.").

[23] Braithwaite, *supra* note 17, at 20 (noting, "By the mid-1980s there were some fifteen thousand nursing homes in the United States, a thousand of them owned by the largest chain . . . .").

[24] *Id.*

> subjected to surveillance from the nurses' station in such homes. Residents whom it is thought unwise to leave unsupervised in their room are put into, often tied into, a wheelchair and positioned adjacent to the nurses station.[25]

The nature of these facilities in the United States is occasioned by the "well-meaning desire to protect residents from harm and to protect the nursing home from legal allegations of negligence."[26] There may be a correlation between the amount of regulation on this industry and the model used to provide care to residents.[27]

The impetus for the move to the private for-profit model in the United States came with the creation of the Medicare and Medicaid programs.[28] With the motivation of profit, we began to see the development of regulatory oversight and standards.[29] This led us to a model that is risk-management based, in this author's opinion, with the physical plant and the staff actions designed to reduce the risk of the facility being sued, giving an institutional feel to the facility.[30]

So today, as a result of these developments over time, some conclusions can be made about the American model for nursing homes:

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[25] *Id.* at 42. The author acknowledges "almost all American nursing homes are designed as surveillance institutions." *Id.* (citing to Albert J. Reiss, Jr., noting "that this is a more general American medical institutional model . . . ."). Michael Foucault, *Discipline and Punish: The Birth of the Prison,* translated by A. Sheridan. (London: Allen Lane 1977).

[26] *Id.* at 43.

[27] *Id.* at 45 (discussing the "large regulatory risks . . . [that lead to] the logic of regulatory risk management. That means that highly disciplined institutions in which risks (*read* people) are monitored, recorded, and subjected to preventive controls (or at least the appearance of preventive control, so that the organization can be seen not to have neglected the risks embodied in the five-hundred-plus standards") (emphasis in the original).

[28] *See, e.g.*, VLADECK, *supra* note 7, at 4.

[29] 1987 Omnibus Reconciliation Act (OBRA '87) (included the Federal Nursing Home Reform Act).

[30] *See, e.g.*, Robert Wood Johnson Foundation, *The Green House Project*, https://www.rwjf.org/en/how-we-work/grants-explorer/featured-programs/the-green-house-project.html (last visited Sept. 22, 2019) (noting that the Green House Home project moves away from the institutional feel of a nursing home).

> Nursing homes continue to be organized as health care facilities, although relatively little actual health care is provided there. They continue to be organized around health professional hierarchies, although relationships in nursing homes should be very different from those in other parts of the health sector. Care planning is still driven by an enumeration of residents' deficits, not their capabilities. And everyone who works or resides in a nursing home (if they are capable of rational consciousness) is conscious of the general perception that nursing homes are facilities of last resort.[31]

Further, "[r]ecent years have seen a small number of exciting, and well-publicized, efforts to alter the culture of nursing home care in ways more consistent with the now fifteen-year old recognition of the Institute of Medicine committee that nursing homes remain, at root, fundamentally residential facilities."[32] Additionally, consider these points to facilitate the recognition of today's model of a nursing home: "[t]he nursing home structure is dominated by the Medicaid system, which is essentially a program for sick people who are poor. These characteristics encourage a culture laden with the trappings of healthcare and medicine. . . ."[33]

There have been some attempts to move away from the "medical model" layout for nursing homes or what we may refer to as the traditional nursing home[34] Although this article's focus is on

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[31] Bruce C. Vladeck, Unloving Care *Revisited: The Persistence of Culture*, *in* 2 J. SOC. WORK LONG-TERM CARE and CULTURE CHANGE IN LONG-TERM CARE, *supra* note 8, at 3.

[32] *Id.* at 8.

[33] Fahey, *supra* note 8, at 40.

[34] *See generally* Siobhan S. Sharkey et al., *Frontline Caregiver Daily Practices: A Comparison Study of Traditional Nursing Homes and The Green House Project Sites*, J. AM. GERIATRICS SOC'Y 1, 1 (2010) (discussing attempts since 1990 to move away from institutionalization, comparing the Green House (GH) home to traditional SNF, and describing the GH focus: "GH homes aim to

the students' trip to De Hogeweyk, there are two models in the United States that are worth mentioning. The first, developed in the early 1990s by Dr. Bill Thomas and his wife,[35] is the Eden Alternative,[36] which emphasizes a collaborative care approach designed to give an elder an improved quality of life.[37]

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deinstitutionalize long-term care and create a supportive environment for elders"). The authors concluded that "[t]he GH model allows for expanded responsibilities of CNAs in indirect care activities and more time in direct care activities and engaging directly with residents." *Id.* at 6.

[35] Eden Alternative, *Our Team*, http://www.edenalt.org/our-team/ (last visited Sept. 22, 2019).

[36] Eden Alternative, http://www.edenalt.org/ (last visited Sept. 22, 2019).

[37]

> In a culture that typically views aging as a period of decline, the Eden Alternative philosophy asserts that no matter how old we are or what challenges we live with, life is about continuing to grow. Building on this new paradigm, it affirms that care is not a one-way street, but rather a collaborative partnership. All caregivers and care receivers are described as "care partners," each an active participant in the balance of giving and receiving. Together, care partner teams strive to enhance well-being by eliminating the three plagues of loneliness, helplessness, and boredom.
>
> Focused on changing the culture of care since the early 1990's, this approach to person-directed care initially came to life in nursing homes and has since expanded its reach to all care settings, including home care and residential care for people living with different abilities. The Eden Alternative firmly believes that culture change unfolds one relationship at a time, and that deep change can only take root when the entire continuum of care is involved. Through education, consultation, and outreach, it currently offers three applications of its principles and practices to support the unique needs of various living environments, ranging from the nursing home to the neighborhood street.

Eden Alternative, *About*, http://www.edenalt.org/about-the-eden-alternative/ (last visited Sept. 22, 2019).

The second, The Green House Project, [38] closer in design to De Hogeweyk, also was developed by Dr. Bill Thomas.[39] The green house home "[p]rovides a home for 10-12 people, with private room/baths, that harmonizes with the neighboring community [and creates] a real home environment with an open kitchen, great room, and easy access to the outdoors."[40] The approach to this type of nursing home can be described as "creat[ing] a small intentional community for a group of elders and staff."[41]

Dr. Thomas describes the evolution of the Eden Alternative to the Green House Model as follows:

> [T]here is a need for an even more daring approach to the problem of reinventing the long-term care environment for the 21st century. We must change the way we think about, regulate and deliver services to people who are coping with difficult changes that often accompany old age. The facility-based approach, which has dominated American long-term care for the past three decades, is not keeping pace

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[38] The Green House Project, https://www.thegreenhouseproject.org/ (last visited Sept. 22, 2019). The green house project mission is to

> envision homes in every community where elders and others enjoy excellent quality of life and quality of care; where they, their families, and the staff engage in meaningful relationships built on equality, empowerment, and mutual respect; where people want to live and work; and where all are protected, sustained, and nurtured without regard to the ability to pay.

The Green House Project, *Vision/Mission*, https://www.thegreenhouseproject.org/about/visionmission (last visited Sept. 22, 2019).

[39] Dr. Bill Thomas, https://drbillthomas.org/ (last visited Sept. 22, 2019); *see also, e.g.,* Robert Wood Johnson Foundation, *supra* note 30 (explaining that the project was supported by the Robert Wood Johnson Foundation).

[40] The Green House Project, *Discover*, https://www.thegreenhouseproject.org/about/discover (last visited Sept. 22, 2019).

[41] Sharkey et al., *supra* note 34, at 1 (citing J Rabig et al., *Radical Re-Design of Nursing Homes: Applying the Green House Concept in Tupelo, MS*, 46 GERONTOLOGIST 539 (2006); RA Kane et al., *Resident Outcomes in Small-House Nursing Homes: A Longitudinal Evaluation of the Initial Green House Program.*, 55 J. AM. GERIATRICS SOC'Y 832 (2007)).

> with society's rising demands for quality of care and quality of life.[42]

Another project, with some similarities to De Hogeweyk, was explained by Clari Gilbert and Gails Bridges:

> Prior to the beginning of this change program in December, 1999, each floor of the Center for Nursing and Rehabilitation operated under the auspices of Directors/Department Heads according to the traditional medical model. The main objective in seeking fundamental change was to establish a warmer, more friendly, resident-centered environment in which all staff, residents and families are mutually interactive in providing and receiving care and services, thus promoting better quality of life and increased satisfaction for everyone involved.[43]
>
> The concept of resident-directed care was first introduced to the Center in 1997 . . . by one of its pioneers . . . . The concept heightened our awareness of the need for a new approach to increased resident involvement in their care.[44]

* * *

> Ten neighborhoods are home to 20-24 residents. Each neighborhood has a shared staff of about 18 people including: a neighborhood coordinator, resident assistants, recreational therapists, food and

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[42] William H. Thomas, *The Evolution of Eden*, *in* 2 J. SOC. WORK LONG-TERM CARE and CULTURE CHANGE IN LONG-TERM CARE, *supra* note 8, at 146.

[43] Clari Gilbert & Gails Bridges, *Center for Nursing and Rehabilitation- Culture Change in an Urban Environment*, *in* 2 J. SOC. WORK LONG-TERM CARE and CULTURE CHANGE IN LONG-TERM CARE, *supra* note 8, at 234–35.

[44] *Id.*

> nutrition workers, a social worker, nurse, spiritual care worker and housekeeper. All staff routinely multi-task to help residents with any need including going to the restroom, brewing coffee, doing laundry, fixing a sandwich, and eating. This kind of highly capable staff that shares tasks supports resident independence and choice.[45]

III. OUR VISIT TO DE HOGEWEYK

Our visit to De Hogeweyk started with a lecture and PowerPoint presentation by Eloy von Hal, who walked us through the principles and pillars of De Hogeweyk concept. There are six pillars arranged under the umbrella of quality of life.[46] The pillars are: favorable surroundings; life's pleasures and the meaning of life; employees and volunteers; health; organization; and lifestyle.[47]

A. Pillar: Lifestyle

The lifestyle pillar uses "norms and values" as the foundation for the resident's lifestyle.[48] Norms and values are typically determined individually when the person is in his or her 20s, and now, in later life, living in accordance with one's lifestyle offers an individual validation.[49] De Hogeweyk uses a broad understanding of the meaning of lifestyle, including one's reading

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[45] *Id.* at 252; *see also* AMY E. ELLIOT, PIONEER NETWORK CASE STUDIES: PROVIDENCE MOUNT ST. VINCENT- A CASE FOR SUSTAINABILITY, http://designonadollar.org/Data/Documents/MountCaseStudy.pdf.

[46] Based on photos of the PowerPoint slides from the presentation by Eloy von Hal (photos on file with lead author). The content of the presentation was similar to Eloy van Hal, *A Vision and the Outcome: De Hogeweyk*, CLPNA Think Tank (Oct. 23, 2014), https://www.clpna.com/wp-content/uploads/2014/12/CLPNA-2014-Think-Tank-Eloy-van-Hal.pdf.

[47] *Supra* note 46, at photo of slide 1.

[48] *Id.* at photo of slide, *Lifestyle*.

[49] *Id.*

materials, food choices, religious beliefs, and the way one communicates with others.[50]

B. Pillar: Favorable Surroundings

Next is the favorable surrounding pillar.[51] This is a widely divergent view from that of the typical SNF institutional model in the United States.[52] Favorable surrounding means "[l]iving life as usual, in a normal house, with a normal household."[53] Using this normal household model, any confusion experienced by a resident is minimized, with life lived on a "normal human scale [by] living together in a small group with people with the same lifestyle."[54] There are staff, referred to as professionals, living there with the residents, helping residents manage a normal daily life.[55]

The physical layout of the residential area is designed to be a home.[56] The living units have what one would expect to find in a home, that is, "a front door, a living room and a kitchen," a private bedroom for the resident, the furnishings in keeping with the style of the resident's prior home, where residents determine cooking meals, housekeeping, and more.[57] Each house has a routine that the residents determine, and the number of residents per home is kept to a small number, typically six or seven.[58] Outside of the home, one finds what one would expect to find in a community: streets, sidewalks, gardens, and places to sit.[59]

Residents are encouraged to be out and about, so both the exterior and interior of the home are designed in a way to "support

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[50] *Id.*
[51] *Id.* at photo of slide, *Favorable Surrounding*.
[52] *See, e.g.*, VLADECK, *supra* note 7.
[53] *Supra* note 46, at photo of slide, *Favorable Surrounding*.
[54] *Id.*
[55] *Id.*
[56] *Id.*
[57] *Id.*
[58] *Id.*
[59] *Id.*

[the resident] to understand where he [or she] is and what is expected of him [or her]."[60] Since residents are encouraged to be outside and to walk around, the actual SNF is built inward facing on the perimeter of a city block with only one secure entrance.[61] The facility design and operating procedures prevent residents from eloping from the facility.[62] The facility is accessible, and "the facades are the safe guards [sic] to the 'unsafe' world outside."[63] Everyone at De Hogeweyk, whether employees or volunteers, is trained to "support a person with dementia in experiencing daily life."[64]

There are also public spaces to De Hogeweyk, not only the walking areas and gathering areas, but areas for shops, physical therapy, classes, and activities. In addition, there is a "backstage" to De Hogeweyk, out of sight of residents and visitors, where employee offices are located.[65]

C. Pillar: Life's Pleasures and the Meaning of Life

The next pillar's focus is on quality of life, but it may be said that all of the pillars have that as their goal. Within De Hogeweyk, this pillar encompasses "meaningful activities, everyday things, [and] normal life" within the home, while outside of the home, it means residents have a social life.[66] A social life may mean meeting others at The Hogeweyk pub or restaurant, involvement in one or more of the 39 various weekly events, attending concerts at the onsite theater, going on a field trip, walking outside, or shopping in the on-premises grocery store.[67] There is an emphasis on being

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[60] *Id.*
[61] Based on lead author's observations.
[62] Elopement in this context means wandering away.
[63] *Supra* note 46, at photo of slide, *Favorable Surrounding*.
[64] *Id.*
[65] *Id.*
[66] *Id.* at photo of slide, *Life's Pleasures and Meaning of Life*.
[67] *Id.*

active, doing normal things one would do, and having the "freedom to wander around" outside of the home.[68]

D. Pillar: Health

The health pillar places an emphasis on the residents' health and quality of life.[69] There are therapists and health care providers there to provide support.[70] The system is much different than that in the United States, explained as a "social-relationship system" rather than a medical model.[71] The goal for De Hogeweyk is the residents' quality of life, while "the extensive program in search for the cure of dementia is [ongoing]."[72] They aim to provide a balanced life of health, living, and wellbeing for residents."[73]

A separate slide, *Quality of Life of People Suffering With Dementia*, looks at quality of life in relation to individual and environmental factors,[74] recognizing as well that family and community, personal freedom, a resident's surroundings, and culture and tradition can have an impact.[75]

E. Pillar: Employees and Volunteers

Everyone at De Hogeweyk, whether an employee or a volunteer, understands and applies De Hogeweyk's vision in their jobs, working independently to achieve the vision.[76] Volunteers are

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[68] *Id.* The wandering is limited to De Hogeweyk premises.
[69] *Id.* at photo of slide, *Health*.
[70] *Id.*
[71] *Id.*
[72] *Id.*
[73] *Id.*
[74] *Id.* at photo of slide, *Quality of Life*. The individual factors include the resident's happiness, health, medications being taken by the resident, and the resident's self-esteem. The environmental factors include offering the resident caring relationships and a social structure, making the resident feel right at home, giving the resident things to do, making sure the resident is independent and has autonomy, and making an appealing physical environment. *Id.*
[75] *Id.*
[76] *Id.* at photo of slide, *Pillar: Employees and Volunteers*.

treated as equals to employees and are always acting under the supervision or direction of an employee.[77]

There is one team placed in every home, and each team consists of six to seven employees. There is one high level professional caregiver on site from 7 a.m. to 10:30 p.m., with one home supporter on site from 8 a.m. to 1 p.m. and one assistant available to support when necessary.[78]

F. Pillar: The Organization

The organization itself is more typical of a business than any other part of De Hogeweyk. The vision is the driver for the structure of the organization as well as its policies.[79] The vision also guides the finances and procedures.[80] Make no mistake, De Hogeweyk is a nursing home, but that facet is hidden, or "back stage," while living a normal life is what everyone sees and experiences, or "front stage."[81] There is a coordinated effort by all of the professionals at De Hogeweyk to "integrate all aspects of life for the resident."[82] The organization is structured to emphasize the life, health, and wellbeing of residents, and all of the professionals at De Hogeweyk work on behalf of the residents to help the residents live a normal and healthy life.[83]

De Hogeweyk philosophy is in contrast to the medical model of institutional care in the United States.[84] Referring to the idea of "operationalizing rehumanization," De Hogeweyk has guiding

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[77] *Id.*
[78] *Id.* The professional caregiver is a "level 3," the home supporter is a "level 1," and the assistant is a "level 2." *Id.*
[79] *Id.* at photo of slide, *Pillar: The Organization*.
[80] *Id.*
[81] *Id.*
[82] *Id.*
[83] *Id.* The slide describes the professionals as working "in service of the resident." *Id.*
[84] *See, e.g.*, VLADECK, *supra* note 7.

principles of deinstitutionalization and transforming and normalizing a resident's life.[85]

G. Rethinking the Model

The final slide in the presentation was titled "Shoot the bears!" meaning consider the intuitional model and turn it on its ear. Change the thinking of health care providers; move away from an organization that emphasizes institutionalization; retrain family to think not in terms of medical and care terms, but instead in terms of quality of life; educate the health care officials and inspectors away from the institutional model of care; look at how care is financed; and revisit the architecture away from the institutional model to the village mode.[86] The last line of the slide suggests: "[e]xplore the boundaries, discuss the intention of the laws, [and] find the human scale."[87]

IV. STUDENT OBSERVATIONS

We had twenty students on this July 26, 2017 field trip to tour De Hogeweyk. As a condition of their participation, they were required to write five-page papers that included their answers to these points: (1) their expectations before the tour, (2) their observations about the features of the dementia village, and (3) their conclusions regarding a dementia village. Some of them also wrote about the feasibility of this model in the United States. The following sections provide excerpts of some of their observations.[88]

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[85] *Supra* note 46, at photo of slide, *Guiding Principles*.

[86] *Id.* at photo of slide, *Shoot the bears!*

[87] *Id.*

[88] The excerpts from the students' essays have been edited for consistency and style, while retaining their individual voices.

A. Expectations Before the Tour

Brittany T. Gibson[89]

Prior to visiting De Hogeweyk Village in the Netherlands, which is also referred to as a "dementia village," I had no knowledge that something of this nature existed. My expectation about the village was that it would be similar to a nursing home in the United States, except perhaps more closed off or private. However, that is not to say that I expected it to be worse than a nursing home; in fact, the term "village" made me feel as if this residence would be more "homey" and similar to a community. In my experience, most nursing homes in the United States are more akin to a medical facility, rather than a comfortable abode for those with dementia.

However, while a dementia village sounds more like a community, I still expected to find a number of medical professionals assisting the residents, such as nurses and other caretakers. I pictured nurses in white uniforms distributing medication. I also pictured a setting where the residents sat around in chairs at a table playing card games, without real enthusiasm, just to pass the time. Essentially, I did not picture the residents as happy, but perhaps more content and accepting of their situation than if they were in a nursing home facility.

Sarah Speicher[90]

Before beginning our four-week study abroad program in The Hague, we were given the opportunity to sign up for a field trip in which we would be touring De Hogeweyk, a "dementia village," in the Netherlands. I was so curious as to what exactly a "dementia village" was that I immediately "Googled" it. I was intrigued by De

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[89] Brittany T. Gibson, J.D., graduated from Charleston School of Law in December 2018.

[90] Sarah Speicher, J.D., graduated from Stetson University College of Law in May 2019.

Hogeweyk's website and this idea of a new kind of nursing home that focused on the residents' previous lifestyles. The website stated that the village was created not to look like a nursing home, although functioning as one, but instead it was meant to appear as a normal residential area. After receiving the email, I was excited to sign up for the tour because my grandmother suffered from dementia, and I spent many years watching the disease consume her while she was living in three different care facilities within the United States; however, I had never seen a nursing home that used this new concept of creating a "village" before.

The website stated that the village offers seven different types of lifestyles: Indonesian, Artisan, Traditional Dutch, High-Class, Cosmopolitan, Christian, and Urban, and the village contains about 23 separate houses, which each are home to six to eight residents. [91]The residents live there together and function as a family unit, sharing a kitchen and a communal living room while each having their own bedroom. Each house eats meals together, and they are encouraged to partake in the daily household chores such as cooking, cleaning, grocery shopping, and laundry. If they want to eat unhealthy food, drink a beer, or smoke a cigarette, they are allowed to make that decision just as they always had been able to prior to moving into the village. The village's main goal is to preserve people's sense of autonomy. If they want to go for a walk outside, stay in bed all day, garden, or ride a bike, they can; the village focuses on giving them the best life to live while suffering from dementia instead of focusing solely on the disease. The beauty of the "dementia village" is that unlike a nursing home, the residents there are free to make their own decisions.

The website gave me a general idea of what a "dementia village" might look like, but I still had so many unanswered questions. The main questions I had were: how do they decide what type of lifestyle someone previously had, how do they incorporate

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[91] *See* Morgan, *supra* n. 59.

that lifestyle into their stay at the village, how does this concept help the residents battle their dementia, how do the residents not get lost or leave the village, and would it actually look and feel like a real village or would it look and feel like a nursing home pretending to be a village? I couldn't wait to go on the tour and see for myself what it was all about!

Ambree Muller[92]

Dementia is not actually a disease. It is a way to describe a variety of diseases dealing with memory loss and affecting everyday activities. "While symptoms of dementia can vary greatly, at least two of the following core mental functions must be significantly impaired to be considered dementia: memory[,] communication and language[,] ability to focus and pay attention[,] reasoning and judgment[, and] visual perception."[93] Dementia is caused by damage to the brain cells, and it is when the brain cells have trouble communicating with each other. Many types of dementia are progressive and start slowly and gradually get worse.

When I thought of a dementia village, I immediately thought of a nursing home, which is what most people would imagine. I knew very little about dementia. Basically, I knew it was a mental disease, and it made you forget things and have mood swings. I knew nothing of how it progressed and how long it took and the different stages that people go through when having dementia.

My first thought upon hearing of a dementia village was that it would be pretty much identical to an American nursing home. I envisioned a hospital-type building with lots of very small rooms with no color or decorations of any sort. I believed that there would

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[92] Ambree Muller, J.D., graduated from Charleston School of Law in May 2019.

[93] Alzheimer's Association, *About Dementia*, https://alz.org/alzheimers-dementia/what-is-dementia (last visited Sept. 23, 2019).

be a lot of nurses and volunteers working with the patients and some families visiting here and there. I had a gloomy outlook on what this “village” would look like with my recollections of the nursing homes I had visited. There are different quality nursing homes depending on the amount you and your family are willing to pay, but no matter how much you are paying, it never feels like a home. It either feels like a nursing home or a very nice hotel.

I believed there would be typical activities such as bingo, dancing, music lessons and other typical activities of nursing homes. In nursing homes, you have a variety of activities, and some people enjoy going to these and others do not, which results in resident having fits that the nurses then have to handle, calm the patients down, and get them back to their rooms. I also believed that like most nursing homes, there would not be very many visitors other than relatives and close family friends.

When we arrived at the dementia village, at first it seemed the same. It was in a growing area. It was surrounded by construction of apartment buildings and condos. You went into a secure door where you saw the front desk receptionist who allowed you in. Once we went through the next door, my entire perception changed. You would assume that once you walk inside, you would be in this nursing home building for the remainder of the time until you walked back out of the front door. This was not the case whatsoever. We walked out of the next door, and we were back outside in what looked like a city center. There were people walking around everywhere, streets, a water fountain, a restaurant, shops, and a theater.

Lauren Riedy[94]

Expectations: U.S. Tort Law v. "Shoot the Bears"?

Before arriving at De Hogeweyk I thought I knew a lot about nursing homes. I would accompany my grandparents to local nursing homes to visit family, friends, and neighbors quite often as a child. I enjoyed visiting—but not for the reasons you'd expect from a child. It wasn't that they were terribly fun, or that I was bribed, or anything like that. I enjoyed going because my young opinion—whether it was imposed on me, formed by me, or a bit of both—had decided that the people living in those facilities led a sad life and that my presence might make it better. I remember the facilities being sterile environments. Serious environments. Quiet. Unfamiliar. Entering those rooms sometimes felt like walking on egg shells. I was careful not to do or say the wrong thing. I was in a medical facility for sick people, after all.

At the age of 25, I joined Alisa Kobrinetz Chernack, an Elder Law and Disability Practice, where I assisted attorneys in matters of Guardianship, Medical Assistance, and Estate Planning regarding the patients of nursing homes in the State of Maryland. As an adult, I learned about the various hurdles that facilities and patients face such as financial, medical, and legal issues that were no doubt underlying reasons for the tension I felt walking into them as a child so many years before.

This background shaped my expectations for De Hogeweyk in a unique way. I was curious about the feeling of the complex. This was still a place for very sick people; my expectations were that it would retain the feeling of gloom that I had experienced in nursing homes before. Despite this, I still

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[94] Lauren Riedy, J.D., graduated from Charleston School of Law in May 2019.

expected the layout of the complex to lighten the mood. I expected to see lots of nurses moving patients around in wheelchairs or people wandering around a bit aimlessly. I still expected the same sterile environment of white walls with lots of railings and ramps—but with perhaps more places to go and things to do.

Some of these expectations were close to reality, but I wasn't really prepared for how the complex would actually look and feel. Burying U.S. tort law principles deep down inside of myself as we walked through the complex, I began to appreciate a theory that the program director was explaining to us. "Shoot the Bears," he said. Confronting issues when they arise instead of instituting too many blanket rules has given the facility a distinct ability to grow in ways that are beneficial to the residents and cultivates a living experience uniquely tailored to them.

Sammy Hall[95]

My interest in visiting the Village was personal; my great aunt suffers from dementia. Not only does she live in a nursing home, but she is confined to the mental health ward of the nursing home despite the fact that she has no history of mental health problems, nor has she been violent towards the staff. To give you some context, my family lives on about 88 acres of rural land in Wrightsville, Georgia, which has been occupied by the Hall family for over 100 years. Most of my family lives there, so although she is my great aunt, she was also my neighbor and a regular part of my everyday life. Upon hearing that she had been locked in the mental ward of the nursing home, I became concerned. I was even more bothered when I learned that she had been hit in the chest by one of the other residents. I spoke to my great aunt's granddaughter to let her know that I am friends with the legal aid attorney who represents our county, but she told me aside from the incident in which my great aunt was hit in the chest, her care from the nurses has actually

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[95] Sammy Hall, J.D., graduated from Mercer University, Walter F. George School of Law in May of 2019.

been better in the mental ward as the more experienced nurses work there and seem to be more attentive. Although this may be true, I still can't help but think it is entirely inappropriate for a person who suffers only from dementia, and who doesn't have a violent history, to be locked away from the rest of the world.

When I was offered a chance to make a visit to the Village, I had not heard of it before, so I immediately did some research to see if I would be interested in the trip. A simple search for the term "dementia village" returned numerous results of news articles and information about this new, pioneering concept in caring for those with dementia, which was being started right outside of Amsterdam in The Netherlands. I was immediately intrigued—a village of people with dementia where people are always monitored by trained individuals, but the people are free to live more normal lives in homes. I found articles detailing that they had their own grocery store and their own beauty salon! I decided not to look into the Village too much because I didn't want to spoil my impression of what I was going to see in person. But my imagination was running wild at this point, thinking about the possibilities that lie within this simple, almost common-sense idea.

No one that I have ever met has ever wanted to go a nursing home; it is almost a joke towards children and their parents: how many of us have joked with our parents about putting them in the nursing home? Of course, that is when we were younger and our parents were younger, so it almost didn't seem like a true possibility. My father is a preacher and does a service at the nursing home once a month; when I accompanied him, I hated going to the nursing home: it smelled like urine, I was always afraid of what the old people would say because they are often brutally honest, and I didn't like the idea of the door locking behind me and not being able to get out without assistance. Even after my own grandmother had her second stroke, her speech was heavily impaired, but she managed to find the strength to beg, "don't put me in the nursing home," which she was able to say multiple times. That is the last thing that she was ever able to communicate, which is why it stands out in my mind; of all the things she could have said, and everything that could have been going through her mind, she focused on the fact that this stroke, which had left her completely disabled, might make her end up in the nursing home.

From these negative thoughts about nursing homes, I began to imagine something quite different when thinking about the Village. My visual image was somewhat like a gated community with houses and streets and small stores just like any other community. I imagined a small town surrounded by a brick fence like a nice, upscale housing development might look in the United States. I also thought about the urban planning concept that is called Atlantic Station located in Atlanta, Georgia. Atlantic Station is considered a model concept for urban planning, which features modern apartments, student housing, clothing stores, a movie theater, a grocery store, and much more all within a small community in midtown Atlanta.[96] Everything you would need is within walking distance.

Hannah M. Yoder[97]

When I first heard the term "dementia village," I pictured a traditional, American nursing home with residents who all suffered from the same awful disease: dementia. Being familiar with the American nursing home culture due to older family members who have resided in them before, I did not expect much of a difference when comparing these homes to the dementia village that I would visit in the Netherlands. I had imagined that it would be easier for the caregivers of such a facility to be able to deal with residents who all suffered from dementia, being able to expect the unpredictability of their behavior and dealing with similar circumstances for each

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[96] *See* https://www.atlanticstation.com/.

[97] Hannah M. Yoder, J.D., graduated from Stetson University College of Law in May 2019.

inhabitant of the "village." Moreover, I thought that the dementia village would be more enjoyable for its residents, being able to be surrounded by others who were in their same condition and being able to recognize the mental state that they were in by understanding the incapacity of other inhabitants when fully alert. In other words, I expected the dementia village to be a nursing home where all residents had one disease in common, making the institution easier on the caregivers and on the elderly who had dementia.

I expected group activities to occur such as movie nights, music performances, painting sessions, and even children or groups to come and visit the elderly, just as a nursing home in America would. However, I did not expect the tailored nature of these activities to conform to the interests of each inhabitant of the dementia village. From my experience with American nursing homes, these activities are available to the entire home as a whole, never honing in on what a particular inhabitant may be more interested in compared to another. Also, from my experience, if a person in an American nursing home had dementia, specific accommodations were not made for the person in order to adhere to the person's needs. For example, if an individual believed that she was currently living in a different era than she was actually in, the caregivers in America, in my experience, would not go to great lengths to conform to her thought process. This proved to be much different in the Netherlands at the dementia village.

Christina Morelli[98]

"My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style."[99] *Thriving* not just surviving, as quoted from Maya

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[98] Christina Morelli, J.D., graduated from Stetson University College of Law in May 2019.

[99] Quote from Maya Angelou, https://www.goodreads.com/quotes/11877-my-mission-in-life-is-not-merely-to-survive-but.

Angelou, is a right that all ages should be given the opportunity to live out.

My expectations for De Hogeweyk, admittedly, were founded on what I know of our health care centers in the United States. I envisioned a building, with sterile hallways, uniform rooms, and set policies. Those who visit would need to be within the hours established for visits, would need to sign in, and would need to follow the signs on the walls for the room number. As they would maneuver through the hallways, they would pass an employee in a scrub-like attire pushing a resident with clipboard in hand. Once they would get in the room, they would walk past the bathroom and an unfamiliar person to get to the resident they had come to visit. The beds would be side-by-side, separated by the privacy of a cloth. The room would have the standard furniture, maybe with some cards or flowers the resident decided to display. They would sit in one of the two chairs and would time out their conversation to end before the scheduled dinner time. They would start out their visit by showing pictures of the dog the resident had to leave behind and would end it with a hug in the crowded hallway surrounded by those trying to make it to dinner. My expectations were based on what I had witnessed with my own grandparents. They were fed, given medicine, and abided by the schedule.

On July 26th, we drove past construction and large corporate structures until our bus finally pulled up along a one-story brick building. We filed out to enter through a revolving door, followed by a reception desk, and next past the security of one more glass door. De Hogeweyk, or “Dementia Village” coined by Fox News, is a community of individuals living with [advanced] Dementia.

Elizabeth Hauber[100]

When I first learned about the village, I was not sure quite what to expect. I did not do any research prior to touring the village. I thought that it would be a simple village wherein its residents would have less freedom to do as they liked. I pictured something much more stage-like (even if the speaker for the group did explain the village to have something akin to a "backstage," this backstage was much less apparent than I anticipated); I was certain that there would be evidence that would make it glaringly obvious that it is just some sort of glorified nursing home, wherein much of the financial costs went into appearance and nothing more. I had a vision of residents walking about with either walkers or being pushed along by nurses in wheelchairs to various storefronts and the staff handling everything else from there. Of course, much of the facility would be outdoors, but it would still just be a nursing home—although with nicer facilities and slightly more autonomy granted in terms of where the residents would like to be at some specified time. I expected a much more stringent level of regulation and certainly nothing like the villagers safely cooking or cleaning for one another.

I did not expect many other amenities besides what usually can be seen in a nursing home (for instance, there is usually a list of scheduled events people may attend, organized by the staff). Additionally, in nursing homes, it is fairly evident as to where administration offices and other employee facilities are located. This makes sense in that context, of course, as it is important that visiting families should be able to easily locate and speak with personnel if necessary. Overall, I expected something much more similar to a nursing home than how it was in actuality: a much more confined living area kept within a building, with the nursing home residents

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[100] Elizabeth Hauber, J.D., graduated from Stetson University College of Law in May 2019.

under fairly close surveillance for purposes of their health. In general, I did not expect much of an amicable, welcome atmosphere. I definitely did not anticipate residents to be particularly open to our strolling about the village; in fact, I expected something of a negative reaction.

B. Student Observations of the Village's Features

Nola Seekie[101]

Twenty-Three Houses with Twenty-Three Front Doors: How De Hogeweyk Is Changing the Face of Dementia Care

Walk down a typical city block in Holland and you are bound to see the same things—small homes lining the street, a market for local needs, a café, perhaps a garden, greenery, or a statue for added decor. While walking down a street in De Hogeweyk, the view appears to be more of the same. Neighbors would be found interacting with each other over coffee at a café, birds would be heard chirping as neighbors congregated near the fountain. You would also find twenty-three houses with twenty-three front doors. It is neither the city planning nor architecture alone that makes this neighborhood extraordinary, but instead it is the inhabitants of the neighborhood and the ideologies behind the town that make De Hogeweyk remarkable.

In simplest terms, De Hogeweyk is a neighborhood for people living with dementia. Even with the foreknowledge that De Hogeweyk serves as a nursing facility for those with stage five (severe) or stage seven (severe with complicated behaviors) dementia, it is difficult to compare the model used with that of a typical nursing facility. The grounds consist of 23 houses that contain between six to seven residents per house. The house sizes are small enough to allow for family dinners yet large enough for

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[101] Nola Seekie, J.D., graduated from Stetson University College of Law in May 2019.

efficiency. The smaller homes also allow the residents to become familiar with the same faces of housemates and the care team. They are encouraged to spend time together as a unit in their sitting areas, yet the front doors have no locks, and their neighbors or guests are free to visit as they please throughout the day. Residents are grouped together not based on their illness but instead their interests. There are 16 types of homes that the 152 residents can choose from based on their personal style and lifestyle that the residents had prior to moving to the neighborhood. The vast majority of the residents will reside in this home until death. It was therefore important to directors to emphasize quality of life no matter how much longer that would be for each individual.

Upon stepping into the main entrance, you are challenged by the director to "find the nursing home" amongst all that the neighborhood has to offer. The premise of this facility is to mimic daily living as much as possible for those with dementia. The traditional nursing home setting often resembles more of a hospital than neighborhood. However, in this neighborhood, each detail is designed to mimic the life that the residents would have lived were they not diagnosed with dementia. Residents are encouraged to continue to participate in the activities that they once enjoyed. This may include activities that would be frowned upon by most facilities such as having cola or wine with a meal or being allowed to smoke a cigarette after a long day. Rather than focus on what we would consider healthy by general standards, De Hogeweyk emphasizes the quality of life through allowing autonomy.

On the grounds of the facility, you will find a grocery store, movie theater, restaurants, hair salons, and club rooms, among other attractions. The facility is also open to the public. Besides being a facility that can be toured, locals that reside near the neighborhood may eat at De Hogeweyk restaurant or may use part of the facility as their polling place during election times. This was done to allow further education to those outside of the community and to encourage cohesion between the neighborhood and the general public that it surrounds.

The organization offers multiple programs for the residents based on activities that they once enjoyed such as painting or cooking. They are also invited to participate in assisting with the daily maintenance of their household by participating in tasks such as grocery shopping, laundry, or cleaning dishes. Not only does this create a sense of normalcy for the residents, but it gives them a job, which encourages ownership in what directors consider the resident's "last new home." The residents are treated like any other adults; however, they are given any additional resources that might be needed to assist with the completion of tasks.

While residents are encouraged to freely roam around the neighborhood as they please, they are never left completely on their own. Staff, who dress in everyday clothes to further mimic daily living, are constantly aware of their surroundings and the surroundings of the residents. While a home aide may be having a mundane conversation on the lawn with one resident, she is also looking for clues that another wandering resident may have lost her way home from the store and is available to assist her if needed. The residents are not considered patients by anyone there but are instead simply people living with dementia.

Lauren Riedy[102]

<u>Mission: Deinstitutionalize, Transform, and Normalize</u>

When we arrived, the director of the De Hogeweyk led us to a theater area, where he gave our group a very detailed presentation and tour of the facility. Walking through the facility, I was immediately aware of the visual differences of this nursing home

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[102] Riedy, *supra* note 94.

compared to those I saw at home. The typical Dutch ways of life replicated in a tiny world: flower baskets hanging around and the design flow of a neighborhood with normal paving, a main street, and a water fountain. During his presentation, I learned that this facility is a nonprofit organization that treats 152 individuals with severe dementia as the dominant disease.

They use a "people first" approach, a concept that encourages individuals to be described as 'person with dementia' instead of a 'dementia patient' for example. This idea blossoms into the theory, the story, the very concept of De Hogeweyk: creating a living space that is as close to 'normal living' as possible. It prioritizes lifestyle over medicine. That is not to say that medical care is not a top priority—on the contrary, it is one of the most important functions that they serve these aging, sick patients. But because they approached the care of people living with dementia from a lifestyle perspective and not from a quarantined medical perspective, everything that flowed from that idea created a genuinely unique little world where residents can live out the final days, weeks, months, or years their life with dignity.

A Day in Their Wooden Clogs/Shoes

The day in the life of an average resident might go something like this. They have meals together at the dining room table. These meals reflect meals that they have been used to eating their whole lives, unlike meals in institutionalized nursing homes that reflect a cafeteria style setting. Since they are paired in homes based on similar cultures and interests, one house may have a tea time in the afternoon, while another may venture to the restaurant to have an afternoon drink. To the extent that they are capable, they can help with chores around the house. While a home supporter may be fixing the meal for the house, one resident may be helping by peeling potatoes. Another resident may be folding laundry. Another may be fetching an ingredient from the store.

The store. Residents have the freedom to walk here, select items they need, and purchase them on their own. What a novel idea. Each household has a budget to spend at the store, located in an area one might consider akin to a very small mall. They can also spend their own money on extra items here as well. It is in the image of a small convenience store that one would find in the United States.

A Word on Economics

Economics were on my mind too when touring this facility. Holland's National State Insurance pays the cost of each resident in the facility. This includes everything but some obvious luxuries like alcohol or fresh flowers for the household. There can be a bit of money that a resident has to pay back to the state depending on how wealthy the resident is, but the highest amount is 2,600 € for the wealthiest of the population. The facility itself is state funded but not state owned. Again, this facility gets the same amount of money as any other nursing home; the difference merely lies in how they spend the funds allocated to them.

"Everywhere Freedom"

I was really touched by the interactions that we had with residents while the director was giving the group a walking tour of the grounds of the facility. One interaction in particular stood out to me and gave me the impression that this style of caring for the elderly has been a success. A resident waved at the group from a bench she was sitting on as we approached her. The group hesitated while the director bent down slightly to exchange a few pleasantries with her in Dutch. When he turned back to face us, he explained that she wanted him to tell us that this place is "Everywhere freedom." It was a moving moment of the tour that I will not soon forget.

Sarah Speicher[103]

As our bus came to a stop and pulled over onto the side of the road, I saw a one-story building lining the whole length of the block and continuing around to the other side. We walked around to the front entrance, which was located in the middle of the block, which was also the middle of the one side of the building. The front entrance consisted of glass doors that were locked and required someone sitting at a front desk to buzz us in. Once we walked through the front entrance, we quickly exited the building and were back outside. In one glance, I was able to look around and see what appeared to be the cutest little village. To my left were tables with a few people sitting at them having a drink, across from them was a sign that said "tavern" and another that said "restaurant," to my right I saw a sign that said "theater," and in the middle was a large fountain. The trees were filled with brightly colored decorations, the sun was shining, and I saw elderly people sitting on some scattered benches, standing by the fountain, and just walking around.

As we began our tour, we first entered the building labeled "theater." With a functioning bar in its lobby, a large stage, and red curtains, it felt like a real theater and not just another room in a nursing home that they called the "theater." After exiting the theater, we were again back outside hearing the relaxing sound of the fountain, and we walked through the village center, past the restaurant and pub and entered into another set of large glass doors. We were then inside a pretty building with lots of glass windows and fun summer decorations. Inside this building was the village "supermarket." The supermarket was a fully functioning market with shopping carts and a cashier, and it contained all the essentials and more. As we all quickly noticed the shelves filled with cans of beer and bottles of wine, we were again reminded of the village's

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[103] Sarah Speicher, *supra* note 90.

main concept to allow people to make their own decisions as they had done their whole lives. Across from the supermarket was another room, which was filled with the aroma of delicious baked goods, and we were told that this room was used for the painting and baking club. Equipped with a kitchen and a large table in the center, it was much nicer than any club room I had seen in other facilities.

We continued our tour as we exited through the back of this building and began walking along the perimeter of the building that ran the length of the block, and we saw where all the residential houses were located, each separated by unique and different front entrances. It occurred to me that this one-story building, containing the residential houses, the theater, offices, and the entrance/exit was built to function as a gate. Instead of fencing the residents in so that they could not wander out of the village, the building itself kept them confined within the village. I thought this was a pretty cool feature and a very clever way to hide the fact that this was a nursing home, while still functioning as one.

We first saw the Indonesian house, which had a tiny pond surrounded by rocks in the front. Then we saw the traditional Dutch house; the front yard was decorated with an old bicycle, and hanging by the front door was a pair of Holland's famous wooden shoes. Next was the urban house, which had silly cat pictures taped inside one of the resident's windows and had a table and chairs in the front of the house where four women were sitting and chatting. We continued walking around the tiny village, which had plenty of green areas and nice spots to stop and enjoy the fresh air. Circling back to the city center, we walked past more residential houses and down the main street, which featured storefront windows for the hair salon, the physical therapist, and more club rooms. The tour ended back where we had started by the fountain, and we walked back inside the one building where the staff was cautious not to let any residents wander out as we exited through the same glass doors we had entered.

Jenna C. Jordan[104]

Our large group of students did attract a lot of attention from residents as they do not usually see dozens of Americans in their small community; those residents who did inquire about our presence seemed excited that we were visiting, and those who did speak English were excited to talk with us and to learn what we were doing there.

First, I was surprised how easy it was for the residents to go outside and that it was highly encouraged. Residents could leave their houses whenever they pleased and each has a door leading out of his or her apartment to the outside. However, there is a locked wall around the entire Village for safety reasons, so they cannot leave the neighborhood and get lost, but they can do all the wandering around the Village that they would like. Each one of the seven neighborhoods in the village looked a little different depending on the lifestyles of those who live there, and each neighborhood has street names, numbers, and different landscaping or seating areas so that it is easier for someone with dementia to find his or her way around. Plus, every employee and volunteer is trained in dementia care and knows the best ways to go about helping someone with an advanced stage of dementia.

If they ever seem lost or confused, the employees are instructed to help the residents navigate; however, it rarely happens. A few of my colleagues asked questions about the risk of falling with different pavement and landscaping, and the Village's policy allowing residents to go outside both rain or shine, but the Village actually has fewer falls than other nursing homes that are inside because it is set up to resemble what the residents were used to before living in long-term care. When a resident goes outside, they

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[104] Jenna C. Jordan, J.D., graduated from Stetson University College of Law in May, 2019.

are more careful and do not tromp through the landscape, but instead they stay on the path.

The paving and landscaping also resemble the outdoors the residents would have seen before their dementia, and because they are used to the landscaping and are more careful in general when outside, there are fewer falls. Further, there is an installed fountain at the front of the Village, which some might think is a hazard for those with dementia; however, it looks like a typical fountain, and there hasn't been a problem with residents confusing it as a swimming pool because it's a fountain like what the residents were used to seeing in the outdoors before they experienced dementia.

I was expecting the entire village to be inside one large building with lots of hallways, but for it to resemble the outdoors with sounds, lights, and plants. For safety reasons, I thought that the outside would need to be simulated; however, I was quite impressed and shocked to see that the entire village resembles a small town connected by sidewalks, all outdoors. My colleagues and I decided it reminded us of a small college town. It looked nothing like any nursing home I had ever seen before, mainly because the residents were all given their own bedroom, a shared living room, and the ability to roam outside unsupervised whenever they choose.

Second, I was surprised at how many residents were outside. Most of them were chatting and having a cup of coffee or tea and socializing. Some were sitting alone, taking a nap, or just enjoying the sunlight. Most of them were able-bodied and looked happy, which was surprising to me because of the severity of their dementia; however, I was so glad to see them out enjoying the beautiful day. Only five of the over 150 residents were bedridden at the time we were there, which was amazing to me because in the nursing homes I have worked at and visited in the United States, most residents are not mobile or are bedridden. The health and happiness of the residents were inspiring.

Third, I was not aware that the residents were able and encouraged, even, to do instrumental activities of daily living such as grocery shopping, eating out, and doing laundry. Although not required, the residents can continue doing what they liked to do before they moved in, such as cooking, dishes, and laundry. In most nursing homes, the residents are told what to be doing at every hour of every day, and what I liked most here is that a resident can decide what to be involved in and what to do to pass the time.

Jose German Garcia[105]

Autonomy is the main objective for many Western countries regarding guardianship. The goal is to be the least intrusive and restrictive as possible and only intervening when needed and only for an abbreviated time allowing for the most autonomy possible. Full autonomy is desired, but many safeguards are needed to protect the elder with the mental condition. Maximizing autonomy is always the end goal. One innovative example in which autonomy is maximized but still has the safeguards in place to help protect the elderly is shown by a progressive idea implemented in The Netherlands. The Netherlands has created a village consisting solely of dementia patients living amongst each other with workers and volunteers assisting them in their everyday life. The concept is revolutionary. The way it works is that for a person to qualify in living in this village, he or she must be an elder who is deemed to have stage 5 dementia or higher. The specially designed village consists of houses for the elders to live in, each home consisting of elders who grew up in similar lifestyles and can relate to each other. Further, the neighborhood consists of different facilities and areas that the elders may need and have access to, and this includes open streets and gardens for the patients to roam free, a theatre for performances and their own entertainment, a restaurant for them to

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[105] Jose German Garcia, J.D., graduated from Stetson University College of Law in May 2019.

eat and enjoy each other's company, a grocery store in which they can shop for items that they desire through an allowance system that their families grant and leave for them in the village, and even an open bar for the residents to enjoy drinks. This village can be compared to a small college campus in which you live on the campus, you have facilities that cater to your needs, and you have facilities that can entertain you. This village's goal when visiting was simple: for the residents to enjoy full autonomy and not make them feel like they are constrained like they would be in a regular hospice setting. The village, known as De Hogeweyk or commonly termed "Dementia Village," wants to promote autonomy for the residents and allow them to interact in a safe and enclosed area and allow them to live their final years as free as possible but also as safe as possible. The concept is extremely successful since not only does the government fund the building of the community and fully fund the village, but other countries are starting to follow the trend and continue the previous trend of taking care of their elders while still allowing for their autonomy to stay intact.

Elizabeth Hauber[106]

There was also a small shopping area, duplicative of what a typical Dutch storefront would resemble. That the residents had their own budget and were permitted to buy things for themselves also surprised me. It is not that I thought those afflicted with dementia would be incapable of such a thing, but I was surprised by the ingenuity of the idea of normalizing the environment as much as possible so that the residents might go along with their daily lives undisturbed. Once this had been explained, one realizes how imperative it can be for these villages to retain some sense of normalcy in the residents' lives. Going grocery shopping and spending some allocated amount of funds, as well as budgeting this, is a completely normal aspect of life. In addition, it supplies the

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[106] Hauber, *supra* note 100.

villagers with another activity as well as further autonomy in selecting various items for themselves.

Most surprising to observe, overall, was how accommodating the village seemed to be, as well as how easily these accommodations seemed to be supplied. I am sure that each and every resident has very specific needs, yet there was not a moment in which I suspected that any of these needs were being unmet. These sorts of accommodations were not merely something such as dietary restrictions or items aiding in physical assistance, etc., but more lifestyle-oriented. For example, the speaker told the group that a woman who lived there had worked with laundry for most of her life. Therefore, to make her most comfortable in familiar surroundings, they arranged that she should be allowed to do residents' laundry. Another woman knitted for several hours a day, whereas another man could continue smoking (as he had done majority of his life). In this regard, emphasis was placed not necessarily on health and an objective view of what is "best" for the individual, but more on freedom and ensuring their comfort in a manner that is not medically-induced.

C. Applicability to the United States

Sarah Speicher[107]

On our bus ride back home, I immediately started comparing this type of "nursing home" to the ones in the United States in which I had previously spent time visiting my grandmother in. The first place my grandma lived was only an assisted living facility. It allowed residents to make their own choices as to how they spent their days, and they were allowed to come and go as they pleased; however, once they left the large building, all that was outside was

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[107] Speicher, *supra* note 90.

a parking lot next to a busy street. Although it had a full bar, three restaurants, and cost a near fortune, I would much rather live at De Hogeweyk because this fancy assisted living facility did not give you the opportunity to walk around outside, live in a house that you were familiar with, go grocery shopping, garden, ride a bike, and ultimately live a fulfilling life that you were somewhat used to living. It was more like putting an old person in a hotel where he or she was to stay for an indefinite amount of time and the person could leave only by car.

The second facility was only for dementia patients, and it was built around what seemed to be a good concept: each wing of the facility housed residents suffering from different levels of dementia. However, again once the residents were moved in, the only way out was by a car and same with the third facility, which seemed more like a hospital than a home.

De Hogeweyk truly did accomplish its main goal of feeling, looking, and acting like a village and hiding the features that come with being a functioning nursing home. The nurses and staff were all dressed in normal clothes, and the residents were allowed to do as they pleased as long as it was moderately safe. They were not constricted to stay in their bedrooms or houses and were free to roam the village. The way the village was created forced residents to have to walk outside to get places, which was smart because fresh air is so important to people's overall happiness. Although I had seen facilities in the United States that had theaters and club rooms and restaurants, because they were all just different rooms in one building, it still felt like a nursing home and not a residential village. The different lifestyles added unique, personalized, nostalgic living conditions and ways of life within the village for each resident.

This concept is truly remarkable, and I believe many elderly people would be happier living in a village such as this. However, as I walked around this village, I could not help but think that this new approach to replacing typical nursing homes might be more beneficial and enjoyable for people who need nursing home care but are not suffering from severe dementia. As my grandmother's dementia became more severe, it became obvious that she no longer seemed able to comprehend situations occurring around her or able to make decisions for herself. For us, seeing that she was comfortable, safe, and well cared for became our main concerns, not her autonomy because we would tragically witness her mistakenly eating her napkin at dinner if she was not being properly watched. Letting her wander freely around a village would be highly concerning since we knew she was so confused, could no longer make her own decisions, and if given the opportunity to, would likely hurt herself.

In her earlier, milder stages of dementia, a village such as De Hogeweyk would have been a wonderful transition for her and might have been very helpful in prolonging the disease from fully taking over her mind. But De Hogeweyk is only offered to those with severe dementia, and at that level of incapacity, I fear it might not be the most appropriate place. However, as I visited my grandmother, I would look around at the other residents there who were not suffering from dementia and just see the emptiness in their eyes. They would sit inside this building with nurses everywhere in their wheelchairs or with their walkers staring at the same boring walls day in and day out; my heart broke for them. Allowing these people who need 24/7 "nursing home" care, but have their wits about them, to live together in a village such as De Hogeweyk, where they could not feel like they were living out their last years trapped inside a building, is such a positive alternative. Overall, I love the concept of the "dementia village" and am hopeful that societies all over the world will begin to follow the Netherlands' lead in using this type of design to replace their traditional nursing homes.

Jenna C. Jordan[108]

The Village was so inspiring. I hope that the United States can begin to realize what an asset the elderly are to our culture and to value their contributions to our society. Dementia is so common in the United States, and I think it is time that as a culture we respected and treated our elders to the best lives they can live, which includes not dismissing them as not valuable or lazy. It is time we stop locking them up in rooms, giving them little privacy, and not allowing them to be out in the sun for days at a time, but instead to give them a chance at a quality of life and enjoyment of the lives they have left to live.

A few things that were distinctly different at the Dementia Village from nursing home care facilities that I had seen previously in the United States included the following: (1) the employees were dressed like civilians, (2) the residents were smiling and out and about walking, sitting, socializing, biking, and enjoying their days, (3) the residents were not "locked up," or bedridden, but instead encouraged to get outside and enjoy each day, and (4) the residents were encouraged to do everyday tasks such as laundry, cooking, sewing, and other activities they were used to doing before dementia. Just because someone gets dementia does not mean they cannot do any tasks anymore; actually doing the tasks they are familiar with will help them to remember and be themselves again—it brings them back and helps them to recall memories and their lives before dementia. It makes so much sense to me that the Village seeks to normalize the nursing home feel and to make it resemble what their residents are used to. The nurses do not wear uniforms but dress as average people, so as not to make the residents feel institutionalized. The surroundings are favorable to residents, as they can choose where they go and how they decorate their homes. These common and familiar surroundings help to minimize the residents' confusion.

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[108] Jordan, *supra* note 104.

My grandma rarely leaves the house currently but does not have dementia. The three things she does leave the house to do are grocery shop, get her hair done, and go to church. Without them, she would not get out at all. These things are all incorporated into the Village so that its residents can continue doing what they are used to doing, if that is their desire. It makes sense that the traditional nursing home feel would confuse a person with dementia because they do the same thing every day, look at the same walls every day, and see the same people every day. The Village gives them an opportunity to leave the house, see new scenery, see new people, and do different activities every day so that every day is distinct in its own way. In common dementia care, social contacts are often forgotten; however, residents of the Village have a variety of opportunities to socialize in intimate or group settings. They can also take day trips. Further, they have privacy in their own rooms if that is what they desire.

The Village was upbeat and seemed less like a community of people with advanced dementia. I would love if the United States could implement something similar; however, the looming question is how to fund it.

Amika Jeffries[109]

The Netherlands has made great strides in reforming the care of people with dementia. This concept should be implemented in every country with a high elderly population. The United States of America has an increasing amount of elderly people. This would work fabulously in America. America already has retirement communities, so developing an American Hogeweyk is not a far stretch. Conceptually, that is. The biggest difference between The Netherlands and America, is how each country views their taxation.

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[109] Amika Jeffries, J.D., graduated from Stetson University College of Law in May 2019.

De Hogeweyk was funded by the government, meaning the taxes paid by citizens of The Netherlands take care of the citizens of De Hogeweyk. The Dutch agreed that the allocation of funds to De Hogeweyk was a sound idea. Healthcare in general is controversial in America. Americans care more about the prison system, space exploration, and controlling other countries than providing care to the elderly—the elderly who at one time carried America to be one of the greatest countries in the world. The resources are there; it would even provide more jobs. De Hogeweyk would only work in America if the attitude of our government and those who control the country's wealth changed drastically.

Sammy Hall[110]

The Village has 152 residents and although not traditional, is still considered a nursing home in terms of funding from the government. There is a wait list to get in based on the style of living the person is seeking, plus the person must meet the criteria of being a level five or seven stage of dementia, which is considered advanced, to be eligible to live in the Village.

After touring the Village, I am a believer in the concept. But one thing that I have to consider coming from a rural area is if the concept would work for people who are from a rural setting. For example, my great aunt, who is in her seventies, like many women in my rural community grew up in one home, married, and then lived in that home for the rest of her life. Unlike many city dwellers who are accustomed to moving to various homes, many of the people I know have had only two homes in their lives. This makes me wonder: even if the living conditions are far superior in a Village concept than those of a traditional nursing home, would a person from a rural area who had lived in his or her adult home for the majority of his or her life feel comfortable in a new setting? It is personalized to the person's style, but will the person still have a

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[110] Hall, *supra* note 95.

longing for his or her "true" home that will take away from the benefits that the Village concept provides? I imagine if given the choice, most would still choose the Village concept over a nursing home, although there might be some homesickness in the beginning.

My thoughts on the bus ride home from my tour of the Village were also focused on considering how I could help bring this concept to the United States. I am in law school, but with the right connections, could I be the person who would help start and improve the concept in my home state of Georgia? My hometown with a population of 9,000 is probably too small, but the neighboring county is quite large and although still considered rural, would make a great setting to test the concept. Obviously, it would take a great understanding of the regulations, budgets, and government role in nursing homes (and making sure this would still be classified as such).

In conclusion, I can say that I was inspired by my visit to De Hogeweyk; the concept is commonsense, yet it seems extremely innovative in comparison to traditional nursing homes. As I age, I am excited to see if the concept will become more common around the world.

Joshua Castro[111]

Prior to the visit of De Hogeweyk, a common understanding would be that it is simply a nursing home with more freedom. This, however, will bear some connotation to the nursing homes traditionally used in the United States. Perceptions of American nursing homes and elder care will traditionally vary, but the negative ideas of neglect and hospitalization are too common to ignore. One will often imagine tan wallpaper halls lined with hospital-style

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[111] Joshua Castro, third year law student at Oklahoma City University School of Law (anticipated graduation date: May 2019).

"bedrooms" and weathered board games. While this stereotype holds true in depictions on television, horror stories float around the news realm as well. This year alone, one caregiver in an Oklahoma facility was arrested on 17 counts of abuse after bite marks were discovered on a resident.[112] Elder abuse in nursing homes is a valid concern that comes to mind.

In pop culture, American nursing homes are burdened with boredom. *Master of None*, an award-winning program, has an episode dedicated specifically to a grandmother and her escape from her care facility not due to abuse, but out of boredom.[113] From an American standpoint, it touches some of the social issues that come with aging as well, such as the many forms of neglect.[114] While its always the worst light of anything that will stand out most, boredom and sadness are unfortunate expectations with nursing homes.

The pros and cons of a traditional nursing home are simple: costs are lower, and the primary goal is health care. Setting the grim expectations aside, a budget can be more easily spent when treatment is uniform, and obviously not every nursing home in the United States succumbs to elder abuse, as there are genuinely wonderful caregivers across the globe. With all this in mind, this was my expectation prior to visiting or researching De Hogeweyk: a field of human rights needing improvement.

Concerns regarding similarities to infamous nursing home systems are immediately extinguished at De Hogeweyk. While functioning under the same budget, the administration at the caregiving facility has managed to keep the positive fundamentals of nursing homes—health care and supervision—while rebuilding the format literally from the ground up. Unlike a traditional system,

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[112] Katie Higgins, *Oklahoma Care Facility Owner Faces 17 Counts of Caretaker Abuse after Bite Mark Found on Resident* (Jan. 19, 2017), www.fox23.com/news/vinita-nursing-home-worker-accused-of-caretaker-abuse/485533802.

[113] Master of None, Season 1, episode 8 (2015).

[114] *See* Mallika Rao, Master of None *Recap: Call Your Grandma*, VULTURE (Nov. 20, 2015), www.vulture.com/2015/11/master-of-none-recap-season-1-episode-8.html.

however, a groundbreaking level of effort is made to assure that the residents are truly living lives tailored to their lifestyles. An entire community is based out of a structured and supervised neighborhood, as compared to hallways of multiple bedrooms. Several home units are tucked away, varying in design according to the lifestyle needs of the residents, some contemporary, others traditional. Essentially, an effort has been made to include every part of life: a supermarket, restaurant, theatre, and the ability to walk down the street or smoke a cigar. "Living a lifestyle, just like before. Residents recognize each other based on their activities, life experiences and interests."[115]

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With all of the positive elements in consideration, only a handful of factors stand out as risks, which do come into play when considering if this system would function smoothly in the United States. As the caregivers are focused on letting residents live life, they are aware of normal risks that must be accepted. Outside of any treatment facility, anyone has the risk of falling, particularly elders. Throughout De Hogeweyk, there are wheelchairs, but physical therapists do not shadow patients waiting for them to fall. In an American society prone to swoop down on liability, this may be an issue.

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In order for a system like this to work in the United States, some subtle changes may need to be made. The first is the cost. Medicare will not typically cover long-term care,[116] and the medical

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[115] Hogeweyk, *Concept*, https://www.hogeweyk.dementiavillage.com/en/concept/ (last visited Sept. 22, 2019).

[116] *How Can I Pay for Nursing Home Care?*, MEDICARE.GOV, https://www.medicare.gov/what-medicare-covers/what-part-a-covers/how-can-i-pay-for-nursing-home-care (last visited Sept. 22, 2019).

systems of the United States and The Netherlands have several differences. De Hogeweyk has managed to fund their system entirely on the same budget that a traditional nursing home would receive, so the challenge is then in properly allocating U.S. funds. Secondly, liability may need to be addressed, which will unfortunately affect the first hurdle by increasing costs. Whether it be addressing risks contractually or by modifying the healthcare to ensure therapists follow residents (though this would be counterintuitive for the residents' independence), an American society will be unlikely to willingly accept a system with such risks.

Lastly, the requirement of a dementia rating from a physician may be an obstacle for the system in the United States. Perhaps for other health issues, a similar model may be privatized, though it would be likely to have a high price tag. Options such as adult day care, assisted living, and traditional nursing homes have become well established, making the introduction of a new system that much more difficult. Despite difficulties that may occur if the system were to ever take shape in the United States, the quality of life and results shown from De Hogeweyk beautifully demonstrate the need to bring elder care to the public stage where it deserves to be.

Elizabeth Hauber[117]

At first, I was unsure if this sort of setup would work quite as smoothly in the United States. This is because the village is divided up into only seven different lifestyles. This makes sense for The Netherlands, as it is country much smaller than the United States, and the majority of its citizens identify as being "Dutch." However, in the United States, these lifestyles could easily be further divided by culture (of which there are a great many in the United States) and *then* by lifestyle. I'm unsure if the lifestyle of "cultural" would suffice for all these differences. This would result in, however necessary, a huge number of different "lifestyles." This

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[117] Hauber, *supra* note 100.

burden might be eased by a much larger number of villages in general, but this might be difficult to fund. The villages might be located in only particular areas of the country based on "lifestyle"; even then, it would seem somewhat unfair to deny potential residents this opportunity based on their background and how they may or may not be accustomed to living. After all, the crux in the village running smoothly is that the residents feel comfortable and familiar with their surroundings.

Most of the other features surrounding the village were also interesting and seemed as if they would be beneficial if more widely implemented in the United States. Many of the facts that the speaker shared with our group related to physical health and dementia in general, of which I had been unaware of previously. For example, the issue of elders falling particularly caught my attention. It is true that, in the United States, many elders are confined to a wheelchair along with wristband or something similar that denotes them as a fall risk. I was not aware that if they were simply allowed to walk as they had been their entire life that this short of confinement could be avoided. Of course, those who grew up in the Netherlands also seem to be significantly more active later in life as compared to those in the United States.

Additionally, and perhaps harshly, I was surprised to hear that the village has yet to be sued. I am unsure if this would work quite as well, considering the nature of our lawsuits and current insurance companies. Simply walking through the village had me eyeing many of the everyday structures and identifying them as potential tort lawsuits; I'm sure there are some attorneys who would immediately act if an accident were to occur. I especially think that, because of this, many insurance companies would not be eager to take such a risk.

Finally, perhaps tying into the above, the United States seems to place more of an emphasis on medical care in nursing homes. The focus in the United States is more on treatment. For dementia villages to run smoothly, it would perhaps be more solely for families and villagers who do not desire their ailments to be extensively treated (this is not to say that the villagers do not receive necessary medical care). In general, I think it is possible for this sort of arrangement to work, but a few changes to better fit American culture would be necessary. The more difficult questions to answer would regard funding, the law's involvement, and the role of insurance companies in the process.

Jose German Garcia[118]

De Hogeweyk is deemed a success by many critics. It is an innovative and progressive idea that preaches autonomy while still having safeguards to care for the villagers properly. This idea has been seen by many globally who have begun implementing and developing their own version in many countries. When it comes to the United States, the idea would be a wonderful addition and would really push us forward in showing care for our elderly. Even though the concept is progressive and innovative, will it work in the United States? Absolutely not—the major reason being money. These villages throughout, especially the ones in The Netherlands, are completely funded by the government or have high government support. In general, the countries with the dementia villages have a different focus when it comes to health care and services offered, and that is because they offer more of it and have broader benefits for their citizens. There is the argument that the concept works logistically in these countries and would not work in the United States because the population is smaller, and with taxes being higher in these states compared to the United States, they are able to afford it. However, the United States would be able to afford concepts like this if there were a slight tax increase and the spending had a higher

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[118] Garcia, *supra* note 105.

focus on elder care than before. With a much higher population, the slight increase in taxes would allow for the expenses to be covered. However, even if this plan worked, the way we viewed the elderly would still deter having a program like a dementia village because compared to other nations, the United States does not seem to have a high degree of care for their elders. In the United States, it seems that the culture towards the elderly is that they are deemed wise, yes, but most of the time, they are deemed a nuisance, annoying, and are just shoved into local nursing homes to have others deal with them. The elders in various other nations it seems are held to a higher standard and well respected, to the point where their rights are argued, and discussion of having constitutional laws centered towards elders in Western Europe has come up through negotiations, treaties, and conventions.[119] So even if the concept is progressive and innovative, and we get over the economic hurdle, the concept would not work unless there is a drastic change in the culture of how the elderly are viewed and treated in the United States. This is not to say that the concept could never work and will never come to the United States, especially since the United States is beginning to consult on how to prevent elder abuse and on the various avenues for guardianship; however, this idea of a dementia village will not be in the United States anytime soon.[120]

D. Students' Conclusions

Nola Seekie[121]

When speaking with the director of the facility, he initially failed to understand why the neighborhood would seem so cutting edge to the average onlooker. He attributes the success of De Hogeweyk to six core pillars: favorable surroundings, life pleasure

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[119] https://social.un.org/ageing-working-group/.

[120] *Id.*

[121] Seekie, *supra* note 101.

and the meaning of life, lifestyles, health, volunteers and employees, and organization. While on the surface, the concept may seem simple, it is the organization's willingness to follow through with the principles that sets it apart. For example, to fully enjoy life's pleasures, one resident may choose to stop chemotherapy and make the most of his or her last days medication-free. Similarly, the organization realizes that walking is a large benefit to overall health; however, it equally embraces that falling is also a part of everyday life. The neighborhood has been willing to take these and many other brave steps all while working with the same budget offered to all other government-funded nursing homes in the country.

The concepts and methodology used at De Hogeweyk have been met with criticism by some. Some minor concerns include the fact that only a small part of the population with dementia is currently accepted by the facility. There is also the concern that family members or spouses may be separated, as one spouse may meet the qualifications for the organization, while the other does not. The facility is also limited in the type of care that can be provided. Temporary care such as respite care or short-term stays are currently not provided by the facility. Additionally, there remains a continuous waitlist of those hoping to enter the facility. The list is further prolonged as spots become available based on the type of housing that is required.

One of the largest concerns mentioned is that of liability that is assumed by the organization. Some facilities, for example, would fear clients falling more simply because they are allowed to walk around more than they do in other facilities. Additionally, the organization does not attempt to eliminate all safety hazards that may be present in daily life. The streets and sidewalks, for example, are made out of the same materials that one would find on any street in Holland. The facility also has features such as a pond that brings some concern to others when considering the mindset of those with advanced dementia. Furthermore, there are several other organizations that are currently well established that would not be willing to make such radical changes to their already established facilities.

The logistics of such a facility on a global level is something that must be considered as well. While nursing homes in the Netherlands are funded by the government, they are privately owned. While this system is well established in The Netherlands, different health care systems internationally would make it difficult for such a concept to be adapted in other countries.

De Hogeweyk has created a new way to consider how we care for elders. Through the commitment for treating each resident as a human first and viewing the disease second, the staff has ensured that all are treated with the dignity that is deserved. Article 25(1) of the United Nations Universal Declaration of Human Rights states:

> Everyone has the right to a standard of living adequate for the health and well-being of himself [or herself] and of his [or her] family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his [or her] control.[122]

While few people would argue that we have a human right to grow old, few organizations, laws, and regulations are taking necessary steps to ensure that this right is afforded to all. This has led to a request for a convention on aging to deal with the many difficulties and forms of discrimination.[123] While this convention

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[122] Universal Declaration of Human Rights, G.A. Res. 217 A (III), U.N. Doc. A/RES/3/217 A (Dec. 10, 1948).

[123] *See, e.g.,* https://social.un.org/ageing-working-group/.

has yet to be adopted, organizations such as De Hogeweyk are leading in this area by providing the best possible care to those advancing in age through thinking about their unique circumstances and requirements. Other organizations however have followed in the lead of The Netherlands' De Hogeweyk and are creating similar facilities. The leaders of De Hogeweyk have also created a separate department, BE, which focuses on educating others and spreading this model to other homes.[124] They emphasize that a cookie cutter approach cannot be taken, but instead the individual needs of each community must be considered for the model to be successful.

Ambree Muller[125]

As far as the actual town goes, it is a brilliant concept. There is a theater where they can enjoy concerts and shows. There are different social clubs that they can join such as painting, cooking, music, and outdoors. There is a restaurant where they can order whatever they want. There is also a pub where they can go to socialize or grab a drink. This seemed very odd to me because when someone is in the last stages of his or her life, the last thing I believe you would want to do is allow him or her to have things that are unhealthy for them. The way the director explained it to us is that these people are spending the last bit of their lives in this neighborhood, and the idea of the village is to keep their lives as normal as possible, and if they smoked or drank their entire lives, then they should be allowed to do so in the last bit of their lives as well.

Overall, I think this is an incredible program, and I would love to see it become a world-wide thing. I think that it truly gives these people the quality of life that everyone deserves even when faced with such a terrible disease. Realistically, the issue would arise when trying to implement it in different countries. I think idealistically everyone would be on board in making it happen

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[124] *See, e.g.,* https://en.wikipedia.org/wiki/Hogewey.

[125] Muller, *supra* note 92.

especially after they experienced it firsthand as I did; however, issues would arise financially. There has been a fund in place in the Netherlands for the National State Insurance, so adding to it would not be as difficult as creating a fund from nothing. Americans would have a hard time deciding where the money comes from and would have a hard time approving the raising of taxes and other issues that may arise when trying to create a fund. Hopefully, other countries will catch on and figure out the best way to create a fund and make this idea a reality for the rest of the world.[126]

Amika Jeffries[127]

International Elder Law: A Significant Advancement—De Hogeweyk

Most societies agree that every human has the right to live and to have shelter, food, and access to healthcare. However, not every society agrees how to deliver these basic human rights. Even the extent to which the controlling body should be responsible for delivering these rights is controversial. Though there is not yet a perfect society, there are some societies that are leading the way in fixing issues that their citizens face. Those societies are even willing to teach other societies how to implement these services.

The traditional nursing home consisted of beds for the aging population in a bland building. They are often overcrowded and understaffed. The patients eat all the same food, and if there are activities, they do the same ones. They all go outside at the same time for the same amount of time. They even have visitation at the same time, and most patients do not have many family members who could visit them. Most of the day, they sit in a chair or lie in bed. The incidences of injury are very high. The patients usually

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[126] *Id.*

[127] Jeffries, *supra* note 110.

deteriorate in health and die within the year. However, at De Hogeweyk, the people there live, on average, another two and a half years.[128]

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As our professor talked with the receptionist to find the director to give us our tour of De Hogeweyk, I looked through to the other side of the lobby. It was glass as well, so I could see the beginnings of De Hogeweyk. This was the first difference—such transparency for a health facility. The second was the way the citizens seemed. They were lounging in the "town square." There was a fountain of water with floaties in it, lots of trees, and relaxed people bathing in the sun.

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Conceptually, Hogeweyk works because the staff provides premier services, the company has worked out the fiscal factors, and the government has agreed that this is worth it. The director is not the only passionate employee at Hogeweyk. The support staff seem to like their jobs and care about the citizens. It is also a great incentive to work at Hogeweyk because uniforms (white or hospital scrubs) are not allowed because they are not normal or favorable for the familiar surroundings of Hogeweyk.[129]

Hannah M. Yoder[130]

Stemming from the village's philosophy to promote a "real world" atmosphere, I found it fascinating to learn that the village takes minimal precautions to protect its residents from actual events that could happen in "real life" circumstances. For instance, the

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[128] See *Foresight Future of an Ageing Population - International Case Studies Case Study 4: Housing for Dementia and Integrated Care in the Netherlands*, Centre for Policy on Ageing, January 2016; http://www.cpa.org.uk/information/reviews/CPA-International-Case-Study-4-Housing-and-Dementia-Care-in-the-Netherlands.pdf.

[129] *Id.*

[130] Yoder, *supra* note 97.

landscaping of the village is not modified in order to accommodate the elderly. The director of the dementia village explained that this is done in order to benefit the residents by mimicking circumstances that they lived in previously, harping on the underlying theme of the community to make their lives as "normal" as possible. Other ways that this is done in the village that differentiates a dementia village and an American nursing home are through the facilities of the village as well. The movie theatre, the café, and the general common area of the village were designed to make the residents feel as if they are not in an institution designed for them; we were even told that the fountain in the common area of the village was filled with swimming devices to promote that same idea.

In addition, one of the most notable takeaways from the dementia village tour was the actual inhabitants that we were able to meet; they all seemed happy, and I believe that that is the most important aspect of the institution. In that same token, as we were being given the tour, a resident came up to us and acted as if she was part of the tour, and it provided us with a glimpse into just how out of touch with reality the residents can be. Also, as we were leaving the tour, it was fascinating to me that we had to sneak out through an exit that one of the residents would not be aware of in order for the resident to not escape. From this, I was able to see just how important it is for a place like the dementia village to exist. To have a group of people so out of touch with their reality to the point where they do not know where they are or what time it is, it is clear that they need to be treated differently. However, it was interesting to see how despite this reality, the caregivers of the dementia village allowed for their residents to have a lot more independence compared to those of American nursing homes. Residents were even wandering around on their own throughout the tour, again emphasizing the fact that at the dementia village, mimicking real life is a top priority.

Furthermore, the dementia village is completely funded by the government of the Netherlands, which is extremely different compared to the nursing home system of the United States. In America, if one cannot afford a nursing home but possesses too much money to afford assistance from the government, one's options are limited to the point where without a family willing to provide for the person's care, the quality of life of the elderly person is extremely diminished. One of the questions that I had during the tour was if there was some sort of waiting list to have a loved one admitted into dementia village due to the fact that it really is a free institution for the family of the elderly person with dementia. Just as I had expected, there was.

My conclusions regarding the dementia village are that, while it is a great institution to have in Europe, I do not think that the same could be said if it was to be in America. In my opinion, America is a very "sue-happy" place to live when compared to the Netherlands or Europe. At the dementia village, the families of the institutionalized realize that a setting replicating the real world is expected, and thus the streets of the village are not paved to accommodate their impaired mobility, and if one were to fall, the family would surely not blame the village. In contrast, in America, I would predict that a fall due to faulty paving of the institution would leave a lawsuit bound to occur. Also, the hands-on care that is provided in an American nursing home exemplifies the desire for families to rest assured that their loved ones are being watched at all times. While this does not always happen, and elder abuse is the result, the families still expect it from the nursing home that they are paying lots of money to have their loved ones live in. The freedom that is provided at the dementia village shows the difference in mindset of the European families.

Nevertheless, I believe that the dementia village is a great way to have those with dementia finish out their lives. It truly seems as if their specific needs are adhered to, improving their quality of life in their final chapter of life. I was genuinely surprised to see how advanced the facilities were and how similar it was to a plaza in America instead of a nursing home in the States. As mentioned, I believe that the only way the setup of a dementia village would be able to be successful in America would be if some kind of contract were made stating that the village was free of any liability resulting from the lifelike facility. Again, this exemplifies the legal needs of America when compared to Europe, especially The Netherlands.

If I were to ever have dementia or have a member of my family diagnosed with the disease, I know that I would rather die in a place like the dementia village when comparing the village to the nursing homes of the United States. However, I believe that the American culture would never allow for such an institution to exist without strict guidelines of what is to be expected. It certainly was interesting to learn about the factors that contributed to the village's creation, the features of the village, and how I believe that it is truly a unique institution that pays respect to those suffering with dementia.

Christine Morelli[131]

The houses are designed for privacy. Traditional nursing facilities commonly have hallways. From the hallway, you would simply open a door to be in the room of the resident. In De Hogeweyk, there is a hallway, a living room, a kitchen, and another hallway to get to the rooms. Traditionally there are one or two bathrooms in Dutch homes, and this was also incorporated in the design of the quarters. As we toured, we were unable to see inside any of the houses and were further instructed not to look through any windows. This was to protect, respect, and ensure the privacy of those who live there.

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[131] Morelli, *supra* note 98.

Instead of being told what to do and when to do it, members have the independence to do as they choose. Whether it is to go to grab a drink at the bar, get some food at the restaurant, have an outing at the theater, get snacks at the store, or hang out with like-minded people, quality of life is not hindered because of a dementia diagnosis. This village embraces individuals and individuality, allowing them to *thrive*. For the musically inclined, there is a club that has its own room, instruments, and a variety of music. For the artistically apt, there is a club for painting and cooking. Every club has a room that caters to these interests, allowing the members to engage and thrive with those with similar interests.

Brittany Gibson[132]

After the visit ended, I had a feeling of happiness that these residents are able to enjoy such a wonderful living arrangement; I have had the exact opposite feeling every time I visit a nursing home. Thus, my conclusion regarding De Hogeweyk, and the concept of a dementia village in general, is that I believe it would be extremely beneficial to adopt this model worldwide. The positive impact that these villages could have on society and on elders with dementia and their well-being would be substantial. Therefore, it is my hope that this concept can somehow be expanded, and De Hogeweyk seems to be leading the path to fulfilling that ideal.

V. CONCLUSION

As part of the mission of Stetson University College of Law, we strive to "provide . . . a dynamic and supportive scholarly community in which students learn, in and outside the classroom and by example, to become outstanding lawyers and leaders who serve the profession and society."[133] This field trip was an excellent example of how students can learn outside of the classroom. The

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[132] Gibson, *supra* note 89.

[133] Stetson University College of Law, *Mission, Vision and Values*, https://www.stetson.edu/law/about/strategic/mission.php (last visited Sept. 22, 2019).

students' essays demonstrate that they made great strides in understanding the approach to long-term nursing home care in the United States as well as comparing the U.S. approach to another approach, as demonstrated in their visit to De Hogeweyk.

BOOK REVIEW: *ELDER LAW: A GUIDE TO WORKING WITH OLDER AUSTRALIANS* (SUE FIELD, KAREN WILLIAMS & CAROLYN SAPPIDEEN EDS., 2018)

Erin Okuno[1]

Today is the oldest you've ever been, and the youngest you'll ever be again.

~Author unknown

Whether we like to think about it or not, we all are growing older. Indeed, you are older now than you were when you started reading this sentence. Thanks to scientific, technological, and societal advances and changes, people are living longer lives, and average life expectancies have increased.[2] As a result, the proportion of elders is growing around the world, including in Australia.[3] Around 3.8 million people in Australia are 65 or older,[4] and the proportion of people in Australia who are 65 or older increased from

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[1] J.D., Stetson University College of Law. Erin Okuno is the Foreman Biodiversity Fellow and an Adjunct Professor of Law at Stetson University College of Law. She works at Stetson's Institute for Biodiversity Law and Policy, where she assists with the Institute's environmental law education, research, and service activities.

[2] For example, the average life expectancy has increased from 71 in the 1960s to 83. PARLIAMENTARY BUDGET OFFICE, AUSTRALIA'S AGEING POPULATION: UNDERSTANDING THE FISCAL IMPACTS OVER THE NEXT DECADE 3 (2019), https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Budget_Office/Publications/Research_reports/Australias_ageing_population_-_Understanding_the_fiscal_impacts_over_the_next_decade.

[3] Australian Gov't, Australian Inst. of Health & Welfare, *Older Australia at a Glance*, *Demographics of Older Australians*, https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians (last updated Sept. 10, 2018).

[4] Australian Gov't, Australian Inst. of Health & Welfare, *Older Australia at a Glance, Summary*, https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/summary (last updated Sept. 10, 2018).

4% in 1911, to 14% in 2011, to 16% in 2016,[5] and is expected to rise to 20% by 2047.[6]

As the number and proportion of older people have grown over time, the practice of elder law has necessarily developed and evolved as well. Although no single uniform definition exists,[7] elder law essentially involves representing older people and their families.[8] The practice of elder law is not limited to a single type of legal issue. Instead, the practice is holistic[9] and encompasses a multitude of legal issues, primarily "decision-making capacity and substitute or supportive decision-makers; . . . accommodation and in-home care services; . . . income support; . . . financial abuse; . . . estate planning; and . . . discrimination."[10]

In Australia, the Commonwealth and the states and territories have taken important legal and policy actions over the last decade or so to address some of the many, often complex, challenges

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[5] Australian Bureau of Statistics, *2071.0 – Census of Population and Housing: Reflecting Australia – Stories from the Census, 2016* (June 23, 2017), https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Ageing%20Population~14.

[6] Australian Gov't, Australian Inst. of Health & Welfare, *Older Australia at a Glance, Australia's Changing Age & Gender Profile*, at fig. 1, https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians/australia-s-changing-age-and-gender-profile (last updated Sept. 10, 2018).

[7] Rebecca C. Morgan, *Elder Law in the United States: The Intersection of the Practice and Demographics*, 2 J. INT'L AGING, L. & POL'Y 103, 107 (2007).

[8] *Id.* at 105. The National Elder Law Foundation in the United States defines elder law as:

> [T]he legal practice of counseling and representing older persons and persons with special needs, their representatives and families about the legal aspects of health and long term care planning, public benefits, surrogate decision-making, older persons' legal capacity, the conservation, disposition and administration of older persons' estates and the implementation of their decisions concerning such matters, giving due consideration to the applicable tax consequences of the action, or the need for more sophisticated tax expertise."

ELDER LAW: A GUIDE TO WORKING WITH OLDER AUSTRALIANS 10 (Sue Field, Karen Williams & Carolyn Sappideen eds., 2018) [hereinafter ELDER LAW] (quoting Nat'l Elder Law Found., *NELF Fact Sheet*, https://nelf.org/page/NELFFactSheet).

[9] Morgan, *supra* note 7, at 107.

[10] ELDER LAW, *supra* note 8, at 3.

faced by the aging population.[11] For example, in 2016, the Attorney-General of Australia requested the Australian Law Reform Commission (ALRC) to conduct an inquiry and report on "existing Commonwealth laws and frameworks which seek to safeguard and protect older persons from misuse or abuse by formal and informal carers, supporters, representatives and others."[12] The ALRC published its final report, *Elder Abuse—A National Legal Response*, in May 2017.[13] The report provides 43 recommendations concerning laws and legal frameworks to protect older people from abuse and to support their autonomy and dignity.[14] Approximately two years later, in response to some of the recommendations in the ALRC report, the Council of Attorneys-General released the *National Plan to Respond to the Abuse of Older Australians (Elder Abuse)* for 2019–2023.[15] The plan sets five priority areas and provides a framework for the federal government, states, and territories to combat elder abuse.[16] Additionally, in October 2018, the Governor-General established the Royal Commission into Aged Care Quality and Safety[17] to undertake an inquiry and make recommendations to

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[11] *Id.* at 5–8.

[12] AUSTRALIAN GOV'T, AUSTRALIAN LAW REFORM COMM'N, ELDER ABUSE—A NATIONAL LEGAL RESPONSE: FINAL REPORT 5 (May 2017), https://www.alrc.gov.au/wp-content/uploads/2019/08/elder_abuse_131_final_report_31_may_2017.pdf; *see also* ELDER LAW, *supra* note 8, at 7–8 (briefly discussing the ALRC report).

[13] AUSTRALIAN GOV'T, AUSTRALIAN LAW REFORM COMM'N, *supra* note 12; *see also* ELDER LAW, *supra* note 8, at 254 (mentioning the report).

[14] AUSTRALIAN GOV'T, AUSTRALIAN LAW REFORM COMM'N, *supra* note 12, at 9–16, 20–21; Australian Gov't, Australian Law Reform Comm'n, *Elder Abuse—A National Legal Response (ALRC Report 131)*, https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/ (last updated June 14, 2017).

[15] COUNCIL OF ATTORNEYS-GENERAL, NATIONAL PLAN TO RESPOND TO THE ABUSE OF OLDER AUSTRALIANS (ELDER ABUSE) 2019–2023, https://www.ag.gov.au/RightsAndProtections/protecting-the-rights-of-older-australians/Documents/National-plan-to-respond-to-the-abuse-of-older-australians-elder.pdf.

[16] Australian Gov't, Attorney-General's Dep't, *Protecting the Rights of Older Australians*, https://www.ag.gov.au/RightsAndProtections/protecting-the-rights-of-older-australians/Pages/default.aspx (last visited Oct. 22, 2019); COUNCIL OF ATTORNEYS-GENERAL, *supra* note 15, at 7–10. The priority areas are to "build our understanding of abuse of older people, so we can better target our responses[,] build community awareness to create the momentum for change[,] continue to strengthen our service responses[,] help people better plan for their future[, and] strengthen safeguards for vulnerable older people." COUNCIL OF ATTORNEYS-GENERAL, *supra* note 15, at 8.

[17] Royal Comm'n into Aged Care Quality & Safety, https://agedcare.royalcommission.gov.au/Pages/default.aspx (last visited Oct. 22, 2019).

strengthen aged care services in Australia.[18] The Royal Commission has requested input from the public and as of October 2019, has received over 6,700 submissions and more than 4,300 phone calls.[19] The Commission is expected to provide its interim report later this year and its final report in 2020.[20]

In addition to these reports, a significant contribution to the literature on this ever-growing field is *Elder Law: A Guide to Working with Older Australians* (The Federation Press 2018), edited by Sue Field, Karen Williams, and Carolyn Sappideen. Offering a comprehensive survey of elder law and related issues in Australia, the book is meant to be used by a wide audience—attorneys, researchers, academics, students, health workers, aged care providers, and financial professionals, as well as elders and their families.[21] A variety of elder law experts contributed to the book, including practitioners, academics, and other professionals, with decades of experience among them.[22] The book's coverage is extensive; the twenty chapters are arranged into six parts according to different legal issues. In the first part, the authors introduce basic elder law concepts and offer an overview of elder law and the aging population in Australia.[23] They also summarize some of the governmental responses to the country's elder law issues and briefly discuss the practice of elder law in Australia.[24] The remaining parts of the book focus on decision-making, support services and living accommodations, income support and financial abuse, estates, and discrimination, respectively.[25]

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[18] Letters Patent from Attorney-General to the Honourable Richard Ross Sinclair Tracey AM RFD QC and Lynelle Jann Briggs AO, at 2–3, Register of Patents No. 53, p. 48 (Dec. 6, 2018), https://agedcare.royalcommission.gov.au/Documents/acrc-signed-letters-patent-6-Dec-2018.pdf.

[19] Royal Comm'n into Aged Care Quality & Service, *Guidance on Making a Submission*, https://agedcare.royalcommission.gov.au/submissions/Pages/Guidance-on-making-a-submission.aspx (last visited Oct. 22, 2019); Royal Comm'n into Aged Care Quality & Service, *supra* note 17.

[20] Royal Comm'n into Aged Care Quality & Service, *supra* note 17.

[21] ELDER LAW, *supra* note 8, at v.

[22] *Id.* at v, ix–xii.

[23] *See id.* at ch. 1.

[24] *See id.*

[25] *See id.* at ch. 2–20.

One area of great import in elder law is decision-making. The second part of the book includes six chapters on issues related to decision-making, beginning with a chapter that describes the statutory authorities and ways in which tribunals determine guardianship and administration applications, which "are legally [recognized] forms of substitute decision-making for adults with disabilities."[26] The following chapter explains several concepts related to decision-making capacity, which is determined according to statutory and common law from the Commonwealth, states, and territories.[27] The chapter also discusses why it is important for lawyers to understand capacity matters to help serve their clients effectively.[28] The remaining chapters in the second part focus on powers of attorney (used to delegate authority over one's financial affairs to someone else),[29] enduring guardianship (used to appoint someone else to make decisions about one's personal matters in the future),[30] and advance care directives (used to make decisions regarding one's future medical treatments).[31] The second part concludes with a chapter on supported decision-making,[32] which the chapter's author argues is "probably the most significant human rights development in the past decade concerning people with disabilities, and . . . is beginning to become a significant development for older people."[33]

Numerous legal and other considerations surround where and how elderly people live. The book's third part addresses these issues in seven chapters about support services and living accommodations. It begins with two relatively short chapters that describe the Australian National Disability Insurance Scheme (NDIS) and the Commonwealth Home Support Programme

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[26] *Id.* at 14; *see id.* at ch. 2.
[27] *Id.* at 35; *see id.* at ch. 3.
[28] *Id.* at 45.
[29] *Id.* at 48; *see id.* at ch. 4.
[30] *Id.* at 58; *see id.* at ch. 5.
[31] *Id.* at 69; *see id.* at ch. 6.
[32] *See id.* at ch. 7. Supported decision-making is "the provision of assistance to enable a person to make their own decisions." *Id.* at 96.
[33] *Id.*

(CHSP). The NDIS provides funding for ‘reasonable and necessary supports’ to people who meet required age, residence, and disability thresholds.[34] The CHSP “provide[s] entry-level home support” for over one million qualifying frail older people;[35] the goal of the program, which began in 2015, is “to help older people stay independent and in their homes and communities for longer.”[36] The remaining chapters in the third part describe several of the accommodation options for Australia’s aging population, including granny flats;[37] boarding houses;[38] mobile/relocatable homes, manufactured homes, and lifestyle resorts;[39] retirement villages;[40] and residential aged care facilities and home care.[41] The authors explain the relevant terminology, statutes and regulations, contracts and agreements, rights, dispute resolution processes, remedies, and costs, as well as the role of an attorney, for these different types of accommodations.

Another crucial consideration for people as they age is the sources of income that they will be able to use in retirement and the potential risks or threats to those funds. The book’s fourth part focuses on financial matters. It starts with a chapter on government financial assistance.[42] Elders in Australia may be eligible to received

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[34] *Id.* at 110–13; *see id.* at ch. 8. It is expected that the NDIS will be fully operational by July 2020. *Id.* at 110. So far, the program has been implemented in all of the states and territories, with the exception of Western Australia. Australian Gov’t, Dep’t of Soc. Servs., *National Disability Insurance Scheme*, https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/national-disability-insurance-scheme (last updated Aug. 26, 2019).

[35] ELDER LAW, *supra* note 8, at 116; *see id.* at ch. 9.

[36] Australian Gov’t, Dep’t of Health, *Commonwealth Home Support Programme*, https://agedcare.health.gov.au/programs/commonwealth-home-support-programme (last updated Feb. 22, 2019).

[37] ELDER LAW, *supra* note 8, at ch. 10. In this type of arrangement, the elderly parent or parents sell their house and give the proceeds to their children, and the children build an extension or a separate dwelling in which the parent or parents will live. *Id.* at 123.

[38] *Id.* at ch. 11.

[39] *Id.* at ch. 12.

[40] *Id.* at ch. 13.

[41] *Id.* at ch. 14.

[42] *Id.* at ch. 15.

age pensions and benefits,[43] which are administered by Centrelink,[44] as well pensions from the Department of Veterans' Affairs.[45] The following chapters cover Australia's superannuation[46] system, identifying applicable laws and discussing superannuation guarantee arrangements and voluntary savings options,[47] and reverse mortgages,[48] describing their history, how they work, the current market, and the potential benefits and risks.[49] The last chapter on financial issues focuses on elder financial abuse, which "may include fraud, misappropriation of real or personal property, inappropriately accessing bank accounts, assets for care arrangements and the abuse of enduring powers of attorney."[50] The authors note that elder financial abuse has significant legal, social, and economic consequences,[51] and they walk through some of the legal responses available in Australia.[52]

The final two parts in *Elder Law* address estates and discrimination. The extensive chapter on estates considers various estate-planning issues (with an emphasis on elders), such as essential estate-planning documents, different types of assets, an attorney's role in the estate-planning process, testamentary trusts, and family provision claims.[53] The final chapter offers a detailed look at age discrimination, including its meaning; relevant international, federal, and state- and territory-level laws; and some of the main contexts in which age discrimination occurs, including

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[43] The types of benefits include "disability support; sickness and mobility allowances; bereavement allowances; wife pensions; widow B pensions; and carer payments and allowances." *Id.* at 183.

[44] *Id.* at 182. Centrelink is a statutorily created authority that administers several legislative acts and delivers services and benefits. *Id.*

[45] *Id.* at 195–200.

[46] The Australian Taxation Office defines superannuation as "money set aside during your working life for when you retire." Australian Gov't, Australian Taxation Office, *Super*, https://www.ato.gov.au/Individuals/Super/ (last updated Nov. 28, 2018); *see* ELDER LAW, *supra* note 8, at 201.

[47] ELDER LAW, *supra* note 8, at ch. 16.

[48] "Reverse mortgages allow home owners to exchange equity in their homes for a loan that is repaid from the proceeds when the home is sold or the borrower dies." *Id.* at 214.

[49] *Id.* at ch. 17.

[50] *Id.* at 229 (citations omitted).

[51] *Id.* at 225.

[52] *See id.* at ch. 18.

[53] *See id.* at ch. 19.

employment, provision of public goods and services, and caring responsibilities.[54]

Throughout the book, the authors note many of the pertinent laws and policies across the Commonwealth and the states and territories.[55] This is important because the laws and policies that impact older people in Australia are not the exclusive province of the Commonwealth—the states and territories also play a significant role.[56] Many of the chapters provide helpful tables that organize and display the laws or regulations at each level of government.[57] When applicable, the authors also identify consistent legislative themes across jurisdictions[58] and explain when laws, policies, or programs have recently changed, are still developing, or may need to be reformed.[59]

Elder Law also contains several convenient reference sections. The front matter includes a table of cases[60] (listed alphabetically by party name) and a table of statutes,[61] which are arranged by jurisdiction. At the end of the book, the bibliography[62] provides a list of references, and a thorough index allows the reader to locate relevant sections of the book by topic.[63]

The book goes far beyond simply identifying elder law statutes and case law in Australia. The authors describe how elder law issues facing the aging population often are interconnected with other areas of the law, such as criminal law,[64] contract law,[65]

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[54] *See id.* at ch. 20.
[55] *E.g.*, *id.* at 48–49, 70, 128–29, 261, 287–93.
[56] *Id.* at 8–9.
[57] *E.g.*, *id.* at 48–49, 70, 128–29, 155, 261, 262.
[58] *E.g.*, *id.* at 155.
[59] *E.g.*, *id.* at 110–11, 114–15, 120–21, 223, 232–33, 238, 245.
[60] *Id.* at xiii–xv.
[61] *Id.* at xvi–xxviii.
[62] *Id.* at 312–26.
[63] *Id.* at 327–39.
[64] *E.g.*, *id.* at 230.
[65] *E.g.*, *id.* at 156–60, 239.

consumer law,[66] or veterans law.[67] They also raise policy considerations and highlight relevant international or foreign laws and cases.[68] As noted in several chapters, elder law attorneys wear multiple "hats" and may need to highlight for their clients other non-legal considerations, including family and other social dynamics.[69] Additionally, it often will be prudent or necessary to involve professionals from other disciplines, particularly health care practitioners[70] and financial advisers.[71] And the authors explain how many of the topics and issues facing the elderly are not unique to them. For example, guardianship issues may affect children or people with disabilities,[72] discrimination laws are not limited to age discrimination,[73] and people should engage in estate planning[74] and saving and preparing for retirement[75] throughout their lives.

Elder Law has much to offer its readers. The book is current[76] and comprehensive in its coverage of numerous elder law topics by experts in the field. Each chapter begins with historical or background information and provides definitions of key terms and summaries of concepts, which will be particularly helpful to non-attorneys. Importantly for practitioners, the authors provide a great deal of practical information, such as lists of elements or questions for practitioners to consider,[77] best practices,[78] limitations on the attorney's role,[79] background on general legal concepts,[80] relevant case law summaries,[81] and illustrative examples.[82] The book is

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[66] *E.g.*, *id.* at 160.
[67] *Id.* at 195–200.
[68] *E.g.*, *id.* at 57, 64, 69, 78, 94, 97, 105–07, 217, 232, 238, 286–87.
[69] *Id.* at 123.
[70] *Id.* at 39.
[71] *Id.* at 205.
[72] *Id.* at 60.
[73] *E.g.*, *id.* at 300.
[74] *E.g.*, *id.* at ch. 19.
[75] *E.g.*, *id.* at ch. 16.
[76] *E.g.*, *id.* at 180, 187.
[77] *E.g.*, *id.* at 59, 160–63, 190–91, 257.
[78] *E.g.*, *id.* at 51–53, 252.
[79] *E.g.*, *id.* at 203.
[80] *E.g.*, *id.* 157–60.
[81] *E.g.*, *id.* at 296–99, 302–03, 306–08, 310–11.
[82] *E.g.*, *id.* at 256, 257, 266–67, 273.

heavily referenced and contains citations to statutes, regulations, policies, publications, websites, and other sources. Additionally, the book is effectively and logically organized as a whole and within each chapter or topic.[83] The numerous expert authors also contribute to the value and utility of *Elder Law*. The book's main drawback, however, is a somewhat unavoidable consequence of being a compilation with so many different authors—some chapters are easier to read and understand than others because of differences in writing style and extent and depth of coverage. But for the most part, the authors present the information in a manner that should be clear even to those who do not practice elder law or are not knowledgeable about the topics.

All told, *Elder Law* is an up-to-date, accessible guide on the many laws and policies that affect Australia's aging population. Readers will appreciate its practical approach and impressive coverage, and the book should serve as an invaluable resource for practitioners and non-practitioners who want to help protect and assist elderly people in Australia.

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[83] Many chapters also display information in helpful tables. *E.g.*, *id.* at 49–50, 61, 184–90, 274, 275–77.

INTERNATIONAL ELDER LAW RESEARCH: AN UPDATED BIBLIOGRAPHY

This bibliography is an update of the work published in volume 5 of the *Journal of International Aging Law and Policy*. This bibliography is aimed at elder law practitioners and policy makers. As an update, this bibliography focuses on material published within recent years in an attempt to supplement the information gathered in Volume 5.

Elder law, internationally, encompasses the differences in socio-legal systems, the levels of development, and the economic stability, all of which are reflected in a country's policies regarding issues related to aging.

A wide variety of search terms may be used to locate international elder law resources including the following:

- Aged-legal status
- Elder abuse
- Elder law or elderlaw
- Geriatrics
- Gerontology
- Guardians
- Legal assistance to the aged
- Long-term care—(topics)
- Nursing homes
- Older people
- Retirement
- Retirement Communities
- Senior Law

In addition, search terms related to specific legal topics may also be useful in locating pertinent resources. For example,

- Consumer fraud
- Estate planning
- Financial planning
- Health care reform
- Living wills
- Probate law
- Reverse mortgages
- Succession
- Wills

For country specific resources, the name of the country was added to the search term, or the word "international" was added with various search terms to locate more broadly focused materials.

Materials in this bibliography are arranged in the following categories:

Agencies and Organizations that focus on international elder law issues.

Conventions, Documents, and Reports relating to international elder law.

Web Sites, Studies, and Databases with a specific international elder law focus.

Web Bibliographies that provide additional resources related to elder law.

Journal Articles that provide references to articles and titles focusing on international ender law arranged by the following topics:

Health and Quality of Life
Housing Policy

It should be noted that this is a selective bibliography, and no attempt has been made to include every agency, organization, convention, document, report, database, web site, article, or book relating to international elder law. Given the tremendous growth in resources in the area of international elder law such an undertaking is beyond the scope of this bibliography. Rather, this bibliography is intended to serve as an overview of materials published in this field and to provide a starting point for further research in international elder law. The Authors welcome your comments and suggestions regarding this project.

Agencies and Organizations

AGE ACTION
https://www.ageaction.ie/

> As described on the website, "Age Action provides older people with services including Care and Repair and computer training and information. It also campaigns nationally for older people. Age Action strives to ensure that its work is focused on mobilizing, supporting, and empowering older people."

> Age Action Ireland
> 30/31 Lower Camden Street, Dublin 2
> Tel: +353 (1) 4756989
> Fax: +353 (1) 4756011
> Email: info@ageaction.ie

AUSER ITALIAN ASSOCIATION FOR ACTIVE AGING
http://www1.auser.it/

> Auser is an association focused on volunteering and social promotion. It is committed to promoting the aging of older people and enhancing their roles in society.

Auser Nazionale
Via Nizza, 154-00198 Rome
Phone: (+39) 06 844 0771
Fax: (+39) 06 84407777

COUNCIL ON THE AGEING ("COTA") AUSTRALIA
http://www.cota.org.au/australia/default.aspx

As described on the website, "COTA Australia is a national organization representing the rights, needs, and interests of older Australians. COTA Australia's role is to promote, improve, and protect the well-being of Australia's older people as citizens and consumers. It seeks to be recognized by the government, the general community, and the media as representing, advocating for, and serving all older Australians."

COTA Australia
Suite 9, 16 National Circuit
Barton ACT 2600
Phone: 02 6154 9740
Email: cota@cota.org.au

ELDER JUSTICE CENTER
http://www.fljud13.org/CourtPrograms/ElderJusticeCenter.aspx

As described on the website, "The Elder Justice Center ("EJC") is a court program that primarily helps people age sixty or older who are involved in the court system because of guardianship, criminal, family, or other civil matters." The EJC serves as a "model for judicial response to complex issues presented when elders interact with the courts."

Elder Justice Center
George E. Edgecomb Courthouse
800 E. Twiggs Street, Room 481
Tampa, FL 33602

Phone: (813) 276-2726
Fax: (813) 301-3701
E-mail: elder@fljud13.org

HELPAGE INDIA
https://www.helpageindia.org/

As described on the website, "HelpAge India is a leading charity in India that has worked with and for disadvantaged elderly for more than three decades. Dedicated to improving the status for India's senior citizens, HelpAge works in twenty-three states providing medical services, poverty alleviation, and income generation schemes in urban and rural India."

HelpAge India
C-14, Qutab Institutional Area
New Delhi - 110016
Toll Free Elder Help Line: 1800-180-1253
Main Office Phone: 011 41688955-56
Email: headoffice@helpageindia.org

HELPAGE INTERNATIONAL
http://www.helpage.org/

HelpAge International is a global network of organizations that promotes the rights of all older people to lead dignified, healthy, and secure lives. Its mission is to promote the well-being and inclusion of older individuals and to reduce poverty and discrimination among the elderly.

HelpAge International
PO Box 70156
London
WC1A 9GB
Phone: +44 20 7278 7778
Email: info@helpage.org

INSTITUTE OF DEVELOPMENT, AGING AND CANCER

http://www.idac.tohoku.ac.jp/site/

The Institute of Development, Aging and Cancer ("IDAC") aims to clarify basic mechanisms of aging, as well as to control age-related diseases, such as dementia and intractable cancers. Its research topics include molecular mechanisms of aging and self-defense systems, molecular mechanisms of carcinogenesis and cancer growth, and brain maturation and aging.

Institute of Development, Aging and Cancer
Tohoku University 4-1 Seiryocho
Aobaku, Sendai, Japan
ZIP: 980-8575
Phone: +(81) 22-717-8496

INTERNATIONAL LONGEVITY CENTER JAPAN

http://longevity.ilcjapan.org/

The purpose of the International Longevity Center ("ILC") is to study the trends of population aging and low-fertility rates from international and interdisciplinary perspectives. ILC also seeks to share the center's findings, to educate the public, and to make policy recommendations to the government.

International Longevity Center
8th fl, 33ird Mori-Building, 3-8-21 Toranomon,
Minato-ku, Tokyo 105-8446
Phone: +81-3-5470-6767
Fax: +81-3-5470-6768

PUBLIC GUARDIAN AND TRUSTEE OF BRITISH COLUMBIA

http://www.trustee.bc.ca/Pages/default.aspx

The Public Guardian and Trustee ("PGT") is a corporation established under the Public Guardian and Trustee Act. PGT has a unique statutory role of protecting the interests of British Columbians who lack the legal capacity to protect their own interests.

Public Guardian and Trustee of British Columbia
700-808 West Hastings Street
Vancouver, BC V6C 3L3
Phone: 604.660.4444
Fax: 604.660.0374

SOLICITORS FOR THE ELDERLY
http://www.sfe.legal/

Solicitors for the Elderly ("SFE") is an independent, national organization of lawyers, such as solicitors, barristers, and chartered legal executives, who provide specialist legal advice for older and vulnerable people, their families, and their caretakers in England.

Solicitors for the Elderly
Mill Studio Business Centre
Crane Mead, Ware
Hertfordshire SG12 9PY
Phone: 0844 567 6173
Email: admin@sfe.legal

THE ADVOCACY CENTRE FOR THE ELDERLY
http://www.advocacycentreelderly.org/

The Advocacy Centre for the Elderly ("ACE") is a specialty community-based legal clinic established to provide a range of legal services to low-income seniors in Ontario. The legal services include advice and representation to individual and group clients, public legal education, law reform, and community development activities.

Advocacy Centre for the Elderly
2 Carlton Street, Suite 701
Toronto, Ontario, M5B 1J3
Phone: 416-598-2656
Fax: 416-598-7924

THE CENTRE FOR POLICY ON AGEING
http://www.cpa.org.uk/

The Centre for Policy on Ageing aims to raise awareness of issues surrounding all aspects of aging and to support good practice. Its overarching focus is to discover and advocate what older people themselves want and need.

Centre for Policy on Ageing
Tavis House
1-6 Tavistock Square
London WC1H 9NA
Tel: +44 (0)20 7553 6500
Fax: +44 (0) 20 7553 6501
Email: cpa@cpa.org.uk

Conventions, Documents, and Reports

CONVENTION ON THE INTERNATIONAL PROTECTION OF ADULTS (JANUARY 13, 2000)
https://assets.hcch.net/upload/expl35e.pdf

The Convention on the International Protection of Adults applies to the protection of adults in international situations who, due to impairments or insufficiencies of their personal faculties, are not in a position to protect their own interests. One objective of this Convention is to establish co-operation between the authorities of the Contracting States as may be necessary to achieve the protective purposes of the Convention.

HUMAN RIGHTS OF OLDER PERSONS: INTERNATIONAL HUMAN RIGHTS PRINCIPLES AND STANDARDS
https://social.un.org/ageing-working-group/documents/OHCHR%20Backgroud%20paper%202011.pdf

> Human Rights of Older Persons: International Human Rights Principles and Standards is a paper that reviews existing international human rights norms as they apply to older persons. It summarizes relevant work of some international human rights mechanisms (treaty bodies and special procedures) in addressing substantive human rights issues in all regions of the world.

INTERNATIONAL INSTITUTE FOR THE UNIFICATION OF PRIVATE LAW: CONVENTION ON INTERNATIONAL WILLS
https://www.unidroit.org/english/conventions/1973wills/convention-succession1973.pdf

> The Convention on International Wills seeks to provide for greater recognition of last wills on an international level by establishing an additional form of will called an "international will" which, if employed, would dispense, to some extent, with the need to search for the applicable law surrounding last wills.

Web Sites, Studies, and Databases

THE 2015 AGEING REPORT: UNDERLYING ASSUMPTIONS AND PROJECTION METHODOLOGIES (2014)
http://ec.europa.eu/economy_finance/publications/european_economy/2014/pdf/ee8_en.pdf

> This report was prepared to update and further examine age-related expenditure projections based on a new population projection by Eurostat.

AGEING IN LATIN AMERICA AND THE CARIBBEAN: IMPLICATIONS OF PAST MORTALITY
http://www.un.org/esa/population/meetings/Proceedings_EGM_Mex_2005/mceniry.pdf

> This publication focuses on health profiles of the older population and examines evidence for the premise that the health status of older persons has been significantly impacted by the evolution of mortality in Latin American and Caribbean countries.

AMERICAS SOCIETY / COUNCIL OF THE AMERICAS: THE AGING POPULATIONS OF SEVEN LATIN AMERICAN COUNTRIES (2015)
http://www.as-coa.org/articles/weekly-chart-aging-populations-seven-latin-american-countries

> This chart describes the United Nation's predictions as to the proportion of people age sixty-five or older in the seven most populous countries in Latin America.

CANADIAN LONGITUDINAL STUDY ON AGING (2001–CURRENT)
https://www.clsa-elcv.ca

> This study attempts to determine why some people age in a healthy manner and why others do not. The study will follow participants until 2033 or until death. Some data can be accessed on the website.

ELSI–BRASIL: LONGITUDINAL STUDY OF HEALTH AND WELL-BEING OF ELDERLY BRAZILIAN (2015–CURRENT)
http://elsi.cpqrr.fiocruz.br

ELSI (Longitudinal Study on Health and Welfare) is a project run by the Oswaldo Cruz Foundation with support from the Ministry of Health and the Ministry of Science and Technology. ELSI examines over 10,000 individuals age fifty or older. The objective of the project is to provide the Ministry of Health with information for the purpose of changing policy.

ENGLISH LONGITUDINAL STUDY OF AGEING (2002–CURRENT)
https://www.elsa-project.ac.uk

This study is an on-going research project that gathers information on the health, social well-being, and economic circumstances of English elders (fifty years old and older). The presented data goes back eleven years.

GATEWAY TO GLOBAL AGING DATA
https://g2aging.org/?section=homepage

This database provides links to various international studies on aging.

HARVARD UNIVERSITY: HEALTH AND AGING IN AFRICA: A LONGITUDINAL STUDY OF AN INDEPTH COMMUNITY IN SOUTH AFRICA (2013–CURRENT)
http://haalsi.org

This study examines how HIV and non-communicable diseases affect the elder population in South Africa. Moreover, various publications are available on the website.

HEALTH AND RETIREMENT STUDY (1990–CURRENT)
http://hrsonline.isr.umich.edu

Though not international, this study provides a wealth of information that can be used to compare U.S. statistics on elder health with those of other countries.

HOMES AND AGEING IN ENGLAND (2011–2012)
https://www.bre.co.uk/filelibrary/Briefing%20papers/86749-BRE_briefing-paper-PHE-England-A4-v3.pdf

This publication uses data from an English Housing Survey to provide an overview of housing costs and living conditions of elder English people. Specifically, it looks at housing that meets certain standards for elderly people.

INDONESIA FAMILY LIFE SURVEY (1993–CURRENT)
https://www.rand.org/labor/FLS/IFLS.html

The Indonesian Family Life Survey ("IFLS") is an on-going longitudinal survey in Indonesia that examines social, economic, and demographic changes in Indonesia. More specifically, the study examines individual and household level behaviors of Indonesians and patterns of economic development and setback in the wake of the Indonesian crisis of 1998.

THE IRISH LONGITUDINAL STUDY ON AGEING (2009–CURRENT)
http://tilda.tcd.ie

This is a survey of the Irish population age 50 and over and their spouses or partners. Data reports are available on the website

JAPANESE STUDY OF AGING AND RETIREMENT (2007)
http://www.rieti.go.jp/en/projects/jstar/index.html

A joint project between Research Institute of Economy, Trade, and Industry, the University of Tokyo, and Hitotsubashi University. The project collects panel data on elderly people in

Japan regarding their lives and health to establish a sustainable social security system.

LIFE EXPECTANCY GAINS AND PUBLIC PROGRAMS FOR THE ELDERLY IN LATIN AMERICA AND THE CARIBBEAN (2014)
http://www.prb.org/pdf14/TodaysResearchAging30.pdf

This article provides an overview on life expectancy in Latin America and the developments that have contributed to population aging.

MEXICAN HEALTH AND AGING STUDY (MHAS) (2001–CURRENT)
http://www.mhasweb.org/

MHAS is a panel study of health and aging in Mexico. The study is ongoing, but various publications and data are available on the website.

NORTHERN IRELAND COHORT LONGITUDINAL STUDY OF AGEING (2017–CURRENT)
http://www.qub.ac.uk/sites/NICOLA/

NICOLA is an ongoing research project in Northern Ireland. In actuality, no information is yet available, as this is a new study. However, it would be a good idea to keep this one on the radar. It is projected to be complete in 2020.

OFFICE FOR NATIONAL STATISTICS: AGEING
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing

This database is an in-depth data collection site for statistics on aging in the United Kingdom.

OLDER PERSONS IN JAMAICA (2012)
https://www.mona.uwi.edu/commhealth/sites/default/files/commhealth/uploads/EXECUTIVE%20SUMMARY.pdf

The main aim of this study was to assess the health and social status of older persons in Jamaica and to identify the needs of the population. Older persons, 60 years and over, in Jamaica were studied using quantitative, qualitative, and clinical tools.

POPULATION AGEING IN THE CARIBBEAN: AN INVENTORY OF POLICIES, PROGRAMMES AND FUTURE CHALLENGES (2014)
http://www.cepal.org/celade/noticias/paginas/8/14928/lccarg772.pdf

This study offers a demographic analysis of the aging process in the Caribbean by presenting the development of selected indicators from the past to the present and projections into the future covering a time-span of 100 years from 1950 through 2050.

SOLICITORS FOR THE ELDERLY: A SAFEGUARDING STRATEGY FOR RECOGNISING, PREVENTING AND DEALING WITH ABUSE OF ADULTS AT RISK (2016)
http://www.sfe.legal/assets/media/Elder_abuse_strategy_2016.pdf

This is a reference guide aimed at legal professionals, but it also may be useful for others working with older and vulnerable adults. It is not a definitive statement of the law on safeguarding older and vulnerable adults, but it aims to provide signposts for recognizing, preventing, and dealing with abuse and neglect. This reference guide was published by England's Solicitors for the Elderly.

SURVEY OF HEALTH, AGEING AND RETIREMENT IN EUROPE (2004–CURRENT)
http://www.share-project.org

> The Survey of Health, Ageing and Retirement in Europe ("SHARE") is a multi-national, multidisciplinary database on health, socioeconomic status, and social/family networks comprising information from 28 countries and over 120,000 individuals.

THE WELL-BEING OF THE ELDERLY IN ASIA: A FOUR-COUNTRY COMPARATIVE STUDY (2002)
https://www.psc.isr.umich.edu/pubs/books/ElderlyInAsia_fullText.pdf

> The Well-Being of the Elderly in Asia provides a comparative examination of the welfare of the elderly and their sources of support across four Asian societies that differ culturally and in terms of their economic development.

WHO STUDY ON GLOBAL AGEING AND ADULT HEALTH (2002–CURRENT)
http://www.who.int/healthinfo/sage/en/

> The World Health Organization's "SAGE" project is a longitudinal research and data collection project involving China, Ghana, India, Mexico, Russia, and South Africa, with an emphasis on adults age 50 and older. Various links to reports and papers are available on the website.

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