ELTIS.DOC 1/20/2006 11:35:22 AM

PREDICATING DIGNITY ON AUTONOMY? THE NEED FOR FURTHER INQUIRY INTO THE ETHICS OF TAGGING AND TRACKING DEMENTIA PATIENTS WITH GPS TECHNOLOGY

Karen Eltis

As technological advances have improved in recent decades, issues involving privacy, security, and safety have permeated our social consciousness. With the advent of such

Karen Eltis is an assistant professor of law at the University of Ottawa specializing in the areas of law and technology, comparative law, and human rights. She serves as the Director of the school's Civil Law joint degree curriculum, The National Program, and also is currently a visiting professor to the Faculty of Law and Political Science at the University of Rennes, France. Professor Eltis received LLM degrees from both Columbia University, where she distinguished herself as a Harlan Fiske Stone Scholar, and the Hebrew University of Jerusalem. She completed her B.C.L., LLB, and BA degrees at McGill University. Her other recent positions and distinctions include Interim Director of the Human Rights Research and Education Centre in Ottawa and Adjunct Professor at McGill University teaching interdisciplinary courses in law, political science, and constitutional law.

Professor Eltis also formerly served as Comparative Law Clerk to Chief Justice Aharon Barak of the Supreme Court of Israel and the Interim Director of Community Relations for the Canadian Jewish Congress. Her other legal experience includes Policy Research Associate to the Government of Canada and associate positions at law firms in New York and Tel Aviv, specializing in litigation and international arbitration. Professor Eltis' scholarly work has garnered international recognition, highlighted by presentations to the Annual Conference of the British Association for Canadian Studies in 2005 and The Indigenous Bar Association and Quebec Native Women's Association in 2004. In 2006, Professor Eltis is invited to speak on the topic of "Constitutional Guarantees for the Judiciary" at the International Congress of Comparative Law in Utrecht, Holland.

technology, ethical dilemmas that arise suggest that not all progressive technologies, however laudably intended, should necessarily be employed to their maximum utility. In the following article, Professor Karen Eltis examines the potential ethical and social implications of using Global Positioning System (GPS) technology to monitor the movements of elderly Alzheimer's victims and dementia patients. Predicating her analysis on the idea that human dignity stems from the qualities of autonomy and free will, Professor Eltis highlights the suspect nature and potential moral hazards implicit in the practice of tagging and tracking the elderly. She casts a critical light on the wisdom, respectfulness, and advisability of using GPS systems to encumber the freedom and independence of the elderly, while simultaneously noting the perceived benefits of using such technology in this fashion—improved safety of the subjects who may otherwise wander, relief provided to caregivers in their vigilance, and expanded capabilities of institutions and law enforcement in tracking such vulnerable citizens, to name a few. Aiming to inspire new debate on a poignant issue that has been largely overlooked in the technology age, Professor Eltis succeeds in crafting a thought-provoking and insightful piece that causes readers to question their own ethical boundaries and ponder the true value of technology in our society. Ultimately, this article emphasizes the paramount weight that should be given to dignifying the fundamental human rights of Alzheimer's and other afflicted patients, and provides valuable insight into the insidious dangers posed by allowing GPS technology to cross a tenuous moral line.

I. Introduction

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.¹

It sometimes seemed that the minute my back was turned something else would be done without any consultation and always with the comment that it was for her own good and she had been told what was going on.²

At the heart of the concept of "human dignity" lies the assumption that individuals are at liberty to develop both their bodies and spirits in accordance with their will.³ In other words, the concept of human dignity incorporates freedom of choice and

^{1.} Union Pac. R.R. Co. v. Botsford, 141 U.S. 250, 251 (1891).

^{2.} Alzheimer's Soc'y, Making Decisions Alliance—The Campaign for Mental Capacity Legislation, http://www.alzheimers.org.uk/News_and_campaigns/Campaigning/mentalcapacity.htm (last visited Sept. 18, 2005).

^{3.} See Äharon Barak, Supreme Court Justice of Israel, A Constitutional Revolution: Israel's Basic Laws, Address at the University of Haifa (May 18, 1992), in 4 CONST. F. 82, 83 (1993).

ELTIS.DOC 1/20/2006 11:35:22 AM

Number 2 GPS Patient Tracking: An Ethical Dilemma 389

freedom of movement."⁴ But what of those individuals whose autonomy and will are restricted by the ravages of age and disease?

Significantly, the right to dignity flows from man's very humanity, irrespective of his or her cognitive abilities or ability to contribute to society in the traditional sense.⁵ This perspective stands in sharp contrast to the Lockeian view, under which "rights flow from the human capacity for reason and the exercise of reason, [and] qualifies the individual for the exercise of freedom." Central to the concept of human dignity, however, is the sanctity of life as an end unto itself rather than a means for advancing various social objectives, such as practicality or expediency.

The postwar proliferation of constitutional mechanisms world-wide endeavored to safeguard civil liberties with particular attention given to society's most persecuted groups. It has been described as a virtual "revolution." But this revolution of rights, a concerted effort to defend civil liberties, seems to have oddly passed over one group that is no less vulnerable than their above-mentioned counterparts. Like children, the elderly—particularly those suffering from dementia or Alzheimer's—"defy the conventional view of rights as implying fully rational, autonomous individuals who can exercise free choice

See id.

^{5.} See id.

^{6.} Tamar Ezer, *A Positive Right to Protection for Children*, 7 YALE HUM. RTS. & DEV. L.J. 1, 2 (2004) (citing JOHN LOCKE, TWO TREATISES OF GOVERNMENT 304 (Peter Laslett ed., Cambridge Univ. Press 1988) (1690)).

^{7.} Izhak Englard, Uri and Caroline Bauer Memorial Lecture: Human Dignity: From Antiquity to Modern Israel's Constitutional Framework, 21 CARDOZO L. REV. 1903, 1903, 1923–28 (2000).

^{8.} In 1981, the U.S. House Select Committee on Aging issued a landmark report entitled *Elder Abuse (An Examination of a Hidden Problem)*, dealing with elder mistreatment, particularly in noninstitutional settings. The report estimated that four percent of the American aged population (approximately one million people) may be subject to moderate to severe mistreatment. It called elder mistreatment a "hidden problem" that is nevertheless widespread and unreported. John B. Breaux & Orrin G. Hatch, *Confronting Elder Abuse, Neglect and Exploitation: The Need for Elder Justice Legislation*, 11 ELDER L.J. 207, 213 (2003). A decade later, a second report titled *Elder Abuse: A Decade of Shame and Inaction* was issued, concluding that the situation had deteriorated to the point that over 1.5 million people were abused yearly. CHAIRMAN OF SUBCOMM. ON HEALTH & LONG-TERM CARE OF THE H. SELECT COMM. ON AGING, 101ST CONG., ELDER ABUSE: A DECADE OF SHAME AND INACTION XI (Comm. Print 1990).

and require freedom from governmental interference." Therefore, the elderly are often left out of dignity-based rights paradigms.¹⁰

The disinterest that typically envelops dementia-related issues is ever more disturbing in light of the aging population and growing need for serious inquiry into the complex predicaments that this vulnerable population faces. ¹¹ As Bernard Dickens explains, "[w]ith the increasing incidence of Alzheimer['s] disease and similar neurological disorders in an aging population, the need for research on subjects incapable of consent is pressing." ¹² With this in mind, the lamentable lack of research into ethics and dementia in the elderly from a juridical perspective (although this is true for most disciplines) is as confounding as it is staggering.

While elder abuse has increasingly been the object of greater scrutiny, the focus has heretofore been somewhat narrow, addressing only the most obvious forms of domestic or institutional maltreatment.¹³ A far more subtle, and therefore insidious, form of abuse relates to new technologies and their remarkably nonchalant application to the aged.

Too often, it appears, we take the limitations imposed on the civil liberties of the elderly for granted as a presumed natural consequence of their degenerating health and of our well-intentioned, yet paternalistic, desire to ensure their medical well-being. Not surprisingly, this is all the more true with respect to assistive new technologies, which, as their name suggests, tend to be deemed innocuous by reason of their professed supportive finality.¹⁴ However, some patient populations, including the elderly or those with cognitive impairment,

^{9.} Ezer, supra note 6, at 1.

^{10.} *Id.* Ezer's remark that "unlike the term 'individual,' the term 'child' does not stand alone from all others, but necessarily implies a relationship" is also true for those suffering from dementia, who are often dependent on a caregiver (often a family member) and therefore marginalized in terms of the "rights revolution" for that very reason, inter alia. *Id.*

^{11.} See Seymour Moskowitz, Golden Age in the Golden State: Contemporary Legal Developments in Elder Abuse and Neglect, 36 LOY. L.A. L. REV. 589 (2003) (discussing the elderly as a generally neglected group).

^{12.} Don Chalmers, *Research Involving Humans: A Time for Change?*, 32 J.L. MED. & ETHICS 583, 586 (2004) (citing Professor Dickens).

^{13.} Breaux & Hatch, *supra* note 8, at 208.

^{14.} Welsh et al., Big Brother Is Watching You—The Ethical Implications of Electronic Surveillance Measures in the Elderly with Dementia and in Adults with Learning Difficulties, AGING & MENTAL HEALTH, Sept. 2003, at 372–75 ("Electronic surveillance has insidiously seeped into the fabric of society with little public debate about its moral implications.").

Number 2 GPS Patient Tracking: An Ethical Dilemma 391

may be at higher risk of having their rights denied in the name of safety.¹⁵

In fact, one ethicist has all but likened people with severe dementia to animals¹⁶ because they supposedly lack the capacity for hope and future aspirations.¹⁷ He therefore implies that their needs are purely physical, thus rendering any deep discussion of their civil liberties superfluous. Thus, when the limitations on liberties at issue derive from purportedly helpful high-tech health care devices, whose novelty and sophistication tend to obscure the thorny human rights issues they raise, commercial success appears to preempt any rights discussions,¹⁸ as privacy and other basic liberties may be compromised for desperately needed respite and convenience for caregivers. Dignity-related issues somehow dissipate as though they are no longer relevant.

A vivid illustration of this phenomenon—one which this piece aspires to address—is the increasing discussion of routinely fitting Alzheimer's patients (and others) suffering from dementia with tracking bracelets. These devices would be connected to a nationwide police database containing sensitive personal information and would be equipped with GPS technology capable of tracking their every move. ¹⁹ Indeed, personal locators are emerging in the marketplace and could eventually compete with traditional "Safe Return" identification bracelets as a means for tagging and tracking dementia sufferers. ²⁰

The original Safe Return program was discretely initiated over a decade ago by the U.S. Department of Justice (DOJ) and the National Alzheimer's Association in an effort to respond to the threat of wan-

^{15.} Susan Ashcroft-Simpson, *Nurses and the Use of Restraints*, 14 EDUC. & AGEING 75 (1999), *available at* http://www.triangle.co.uk/eda/14-01/Ashcroft.pdf (last visited Sept. 18, 2005).

^{16.} DAN Ŵ. BROCK, LIFE AND DEATH: PHILOSOPHICAL ESSAYS IN BIOMEDICAL ETHICS 372–73 (1993).

^{17.} Id.

^{18.} See A. Michael Froomkin, The Death of Privacy, 52 STAN. L. REV. 1461, 1503 (2000) (remarking that "[c]onsumers who place a low value on their information privacy—people for whom their average valuation is less than the average valuation of a profiler—would have agreed to sell their privacy even if they were aware of the long-run consequences. The only harm to them is that they have not extracted the highest price possible.").

^{19.} See UNIV. OF PITTSBURGH MED. CTR., GPS TECHNOLOGY AND ALZHEIMER'S DISEASE: NOVEL USE FOR AN EXISTING TECHNOLOGY, http://alzheimers.upmc.com/GPS.htm (last visited Sept. 18, 2005).

^{20.} See id.

dering due to dementia.²¹ With Safe Return, the Alzheimer's patient prone to wandering is first registered through the Alzheimer's society itself, which acts as an intermediary, storing vital personal information and faxing the enrolled person's information to local police upon notice that someone is lost.²² The patient is subsequently fitted with a wrist bracelet, necklace, or iron-on clothing labels, allowing her to be tracked by police; the police then use the information for the purpose of returning her to her home if and when the need arises.²³ The purpose of this program, of course, is to assist police in finding a person who has wandered.²⁴ While the objective is unquestionably laudable, the means employed to achieve it may be increasingly suspect. Indeed, cooperation between caretakers and law enforcement using the traditional bracelet,²⁵ or eventually GPS technology,²⁶ is problematic.²⁷

^{21.} Id

^{22.} The information can be accessed by police anywhere in the United States. *See* ALZHEIMER'S ASSOC., ABOUT ALZHEIMER'S ASSOCIATION SAFE RETURN, http://www.alz.org/Resources/FactSheets/SRfactsheet.pdf (last visited Sept. 18, 2005).

^{23.} ALZHEIMER'S ASSOC., ALZHEIMER'S ASSOCIATION SAFE RETURN, http://www.alz.org/services/safereturn.asp (last visited Sept. 18, 2005).

^{24.} Id

^{25.} UNIV. OF PITTSBURGH MED. CTR., *supra* note 19 ("The patient's name, photo, identifying characteristics, and emergency contacts are placed in a database. The patients wear an accessory—a pin, necklace, or bracelet—indicating that they are memory impaired. Then, if the patient is found wandering, a call can be placed to the 24-hour toll-free hotline listed on the Safe Return accessory. Local law enforcement agencies can then use this information to return the wanderers to their homes.").

their homes.").

26. Applied Digital Solutions offers a device called the "Digital Angel," which is worn as a watch. Using GPS mapping software and cell phone networks, the Digital Angel alerts caregivers by e-mail (sent to a cell phone, personal computer, personal digital assistant (PDA), or text pager) when an Alzheimer's patient has wandered out of a predesignated area. Press Release, Digital Angel Corporation, Digital Angel to Enter Beta Test Phase on Highly Anticipated Wanderers Product (Aug. 14, 2001), http://www.digitalangelcorp.com/about_pressreleases.asp? RELEASE_ID=42; see also Aaron Renenger, Satellite Tracking and the Right to Privacy, 53 HASTINGS L.J. 549, 550 (2002) ("GPS is based on a network of at least 24 satellites that continuously send out radio signals transmitting their locations. A GPS receiver back on Earth can then triangulate its three-dimensional position using the information received from at least four of the satellites. The system is accurate anywhere on Earth to within 100 feet. Using a technique called differential GPS, users can obtain accuracies of several feet.").

^{27.} See Suzanne Cahill, Letter to the Éditor, Technologies May Be Enabling, 326 BRIT. MED. J. 281, 281 (2003) (responding to Julian C. Hughes & Stephen J. Louw, Electronic Tagging of People with Dementia Who Wander, 325 BRIT. MED. J., 847, 847–48 (2002)); Desmond O'Neil, Letter to the Editor, Tagging Should Be Reserved for Babies, Convicted Criminals, and Animals, 326 BRIT. MED. J. 281, 281 (2003) (same).

Even more challenging, it will be argued, is the emerging culture of casual, even indifferent, acquiescence to use of such devices.²⁸ Increasingly, society seems to demonstrate a collective failure to even inquire into their appropriateness prior to consenting, as though the desire to protect the frail somehow automatically justifies any rights infringement that the process may entail.²⁹

The use of GPS technology to tag and track Alzheimer's patients, while still in the nascent phases of use, raises more than a few key human rights concerns. Such issues include potential restrictions on the most fundamental rights, notably the rights to liberty, privacy, equality, and, perhaps more importantly, dignity.³⁰ While these concerns generally exist with respect to any privacy-invading technology, the use of GPS technology to assist the elderly is uniquely disconcerting. Tagging and tracking is especially bothersome because of society's aforementioned tendency to disregard seemingly abstract human rights when the technology's declared purpose is for "the greater good," namely safeguarding the elderly and alleviating our own burden in caring for them.³¹ Indeed, it is as if the right to dignity were not a corollary of humanity, but instead predicated on autonomy.

Too often, therefore, health-promoting objectives targeted at the elderly appear to invite an automatic nod to commercially successful new age devices. It seems the case that when it comes to the elderly, technological savvy often preempts any rights discussion, as both medical well-being and the promise of alleviating the burden of an underfunded mental health care system³² implicitly trump liberties.³³

^{28.} Unfortunately, only the absence of literature on point can be cited as support for this assertion.

^{29.} I am of course referring to patients registered by their families. Such patients often protest the procedure rather than those patients who themselves choose to register.

^{30.} See Universal Declaration of Human Rights, G.A. Res. 217A (III), U.N. Doc A/810 (Dec. 10, 1948), available at http://www.un.org/Overview/rights.html. I discuss these rights only briefly, as a more in-depth discussion would exceed the parameters of this article. My purpose here is exclusively to spark discussion by highlighting the issues.

^{31.} Jay Lyma, *AI Devices Serve as Patient Caregivers*, NEWSFACTOR, July 26, 2002, http://www.newsfactor.com/perl/story/18759.html ("[T]he goal of such technologies and devices is to reduce the burden of caring for individuals who live with Alzheimer's...."); GPS Applications LLC, Item Description—WanderCARE 100T, http://gps-applications.com/WanderCare100T.htm (last visited Sept. 18, 2005) ("WanderCARE eliminates much of the stress—and much of the heavy expense of minute by minute close observation of Alzheimer's victims....").

^{32.} Recommendations to Improve Mental Health Care in America: Report from the New Freedom Commission on Mental Health Before the Subcomm. on Mental Health &

In the absence of greater awareness of such issues, elder tagging may simply become the norm or the "reasonable" means for dealing with dementia. Taken to its logical conclusion, it is reasonable to project that, in the long-term, to tag and monitor dementia patients may no longer be merely an option, but rather the rule; those who do not avail themselves of this assistive technology may themselves risk incurring liability in the future.³⁴ Moreover, those still capable of consenting or who leave advanced directives refusing surveillance may risk being denied proper insurance coverage, as they could be deemed unreasonable risk takers.35

While certain restrictions on mobility may be more readily understood (not to say condoned) in light of the "rational objective" of curtailing dangerous wandering and liberating caregivers from twenty-four-hour monitoring duties, accomplishing this goal using the least restrictive means would be preferable. Again, the chief difficulty lies not in the actual use of this assistive technology, but in failing to question the ethics of resorting to the same technologies deployed to keep track of criminal suspects,³⁷ those under house arrest, sexual offenders,³⁸ and animals.³⁹ While the issue of such devices' constitutionality has, to a certain extent, been raised with respect to convicted sex-offenders, 40 its application to the aged has notably escaped serious scrutiny. The reason for this latter silence is twofold. First, as noted above, elder rights tend to be overshadowed by health

Substance Abuse Servs. & the S. Comm. on Health, Educ., Labor & Pensions (2003) (statement of Michael Faenza, President, National Mental Health Association), http://bazelon.org/newsroom/11-4-03mhreformtestimony.htm.

^{33.} Charles Weiss, The Coming Technology of Knowledge Discovery: A Final Blow to Privacy Protection, 2004 U. ILL. J.L. TECH. & POL'Y 253, 256 ("Advances in information technology . . . have eroded the effectiveness of existing constitutional and statutory protections.").

^{34.} *See infra* text accompanying note 60.
35. While it is beyond the scope of this article to furnish a thorough analysis of the insurance considerations related to routine tagging of the elderly afflicted with dementia, the issue is certainly one of relevance which must first be raised in order to spark further debate.

^{36.} Language used by the Supreme Court of Canada in developing its "proportionality test." The Queen v. Oakes, [1986] S.C.R. 103, 106.

^{37.} David A. Schumann, Tracking Evidence with GPS Technology, WIS. LAW, May 2004, at 9.

^{38.} Patricia A. Powers, Making a Spectacle of Panopticism: A Theoretical Evaluation of Sex Offender Registration and Notification, 38 NEW ENG. L. REV. 1049 (2004).

^{39.} See O'Neill, supra note 27, at 281.

^{40.} Editorial, A Fine Line, Indeed, J. NEWS (Westchester County, N.Y.), Aug. 19, 2005, at 4B.

Number 2 GPS Patient Tracking: An Ethical Dilemma 395

concerns.⁴¹ Second, any abuse that does ensue can generally be traced to well-meaning caregivers rather than the state, which effectively precludes any possible recourse.⁴²

At this juncture, emphasizing that the following by no means purports to address the entirety of the multifaceted issue of the ethics of tagging elders suffering from dementia is imperative. In fact, such an undertaking would require a multidisciplinary engagement, destined to study aspects exceeding the purely juridical perspective. Instead, the purpose of this paper is to highlight the need for multidisciplinary study of the problem and to ignite the sort of deliberation essential to addressing a complex predicament unbounded by juridical analysis. 43

II. Balancing Caregivers' Needs with Patients' Liberties: The Need for Multidisciplinary Reflection

Prior to proceeding, it is necessary to pause and recognize the terrible burden, along with the enormous courage, of those who care for their loved ones suffering from Alzheimer's and age-related dementia. Credit is similarly due to the Alzheimer's Association, whose tireless efforts are nothing but laudable. The merits of the Safe Return program are not at issue, and I will not attempt to resolve its continued use here.

While neither suggesting that the Safe Return program be dismantled nor that personal locators using GPS technology be automatically barred from use, this paper will espouse the urgency for multidisciplinary dialogue, leading to the development of a coherent, principled approach to the use of assistive technologies.⁴⁴ From a human rights perspective, such an approach would first recognize the primordial character of personhood and the multiplicity of interests of

^{41.} See Welsh et al., supra note 14, at 3.

^{42.} See infra text accompanying notes 53–57 (state, not private, use of GPS has been deemed illegal), text accompanying notes 65–66 (general unwillingness to burden the caregiver with increased scrutiny or liability), and text accompanying notes 75–77 ("best interests" of dementia patients interpreted to be their safety rather than their civil liberties).

^{43.} So far, the only cooperation detected is that between the caregiver community and law enforcement characterizing location and safe return. *See supra* text accompanying notes 19–26.

^{44.} See Joint Conference on Legal/Ethical Issues in the Progression of Dementia, Recommendations of the Joint Conference, 35 GA. L. REV. 423, 427 (2001) (providing recommendations for a principled approach to dealing with restricting freedoms of those diagnosed with dementia).

the elderly, beyond physical concerns and irrespective of capacity, in order to promote more informed health policy decisions. As health policy expert Bruce Jennings⁴⁵ opines: "Caring and caregiving, after all, are not only about meeting an individual's needs or making him comfortable; they are about the recognition of the person being cared for and the recognition of the caregiver's own personhood therein."46

Moreover, now is an opportune time to consider the impact of new technologies on the most at-risk among the vulnerable—the elderly suffering from some degree of mental incapacity, most commonly Alzheimer's patients. For instance, because we as a population live longer, 47 advocates for the elderly in Canada have voiced an urgent call for a national strategy on Alzheimer's disease and related dementias.⁴⁸ Simply put, the issue cries out for resolution.

Finally, because the matter of dementia rights is, to a certain degree, inseparable from general health care rights, 49 caregiver concerns must not be neglected. If caregivers are tempted to routinely resort to such technologies, it is perhaps due to the onerous burden they face, characterized by lack of resources and assistance. Our health policy must strive to remedy these intrinsic shortcomings to ensure that such technologies, whatever their merits, are deployed as a last and regulated resort. Sober reflection on the long-term implications of routinizing technological surveillance leaves little doubt about the costs of too easily indulging in the temptations of technology—both financial⁵⁰ and in terms of liberties.

^{45.} Mr. Jennings is not a jurist; he teaches at the Yale University School of Medicine in the Department of Epidemiology and Public Health, specializing in The Hastings Ctr., Biography of Bruce Jennings, http://www. thehastingscenter.org/pf/people/jenningspf.asp (last visited Sept. 18, 2005).

46. Bruce Jennings, Freedom Fading: On Dementia, Best Interests and Public

Safety, 35 GA. L. REV. 593, 615 (2001).

^{47.} See Tracy L. Merritt, Note, Equality for the Elderly Incompetent: A Proposal for a Dignified Death, 39 STAN. L. REV. 689, 689 (1987) ("Medical technology now makes it possible to prolong the dying process of severely debilitated elderly patients. The majority of the aged die in hospitals or long-term care institutions, and many are sustained by artificial life-support systems throughout their final days or years

Canadian Press, Health Advocates Call for Alzheimer's Strategy (Oct. 23, 2004), http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/1098554337074

^{49.} See Ronald Dworkin, Justice in the Distribution of Healthcare, 38 McGill L.J. 883, 885 (1993) (discussing advance directives while noting Descartes' belief that health care is the first right).

^{50.} It is possible that an institution's malpractice insurance may rise if they do not adopt a GPS tracking program for their elderly patients.

NUMBER 2 GPS PATIENT TRACKING: AN ETHICAL DILEMMA 397

In view of that, following a succinct overview of GPS technology functioning, Parts III and IV of this article will raise a number of issues potentially responsible for the "legal limbo" relating to the electronic monitoring of dementia patients. Relevant topics include the identity and intentions of the watchers, paternalism and the intersection of interests, and the inappropriateness of traditional legal remedies that is aggravated by definitional difficulties regarding what actually constitutes "restraints." Part V, or "A Final Word," explores prospective recommendations for the purpose of promoting further discussion.

III. Discussion

A. How Does GPS Work?

Born of military necessity, Global Positioning System technology (GPS) allows for state-of-the-art positioning surveillance. While initially limited to Air Force reconnaissance, GPS technology is increasingly coveted in civilian circles. In effect, GPS "tracking devices,"⁵¹ which are easily installed in telephones, vehicles, or even placed on persons, can record, track, and effortlessly locate most any moving target with impressive accuracy by emitting radio signals.⁵²

When deployed by the state to collect evidence, GPS technology is under increasing scrutiny, as evidenced by the leading case on point, *State v. Jackson.*⁵³ Absent state action, however, GPS may be legally used to track property.⁵⁴ The legality of privately monitoring third parties and their property remains to be definitively settled, al-

^{51.} For a thorough explanation of GPS functioning, see Schumann, *supra* note 37, at 9.

^{52.} *Id.* at 10 ("A GPS receiver can record a track, which is a series of periodically recorded fixes that are connected to form a line representing past travel. The GPS user also can save the current fix by pushing a button and marking a 'waypoint,' a named date-and-time-stamped fix that can be retrieved from memory at a later time. Waypoints can be strung together into a 'route,' which a GPS receiver can follow automatically. Tracks are a chronological transcript of travel, and waypoints are like time-stamped notes of events along the way. While both record histories, tracks are more or less automatically recorded, and waypoints take user effort and are easier to reference. Both are valuable as evidence.").

^{53.} State v. Jackson, 76 P.3d 217, 224 (Wash. 2003) (holding that police installation of Global Positioning System device on murder suspect's vehicle infringes upon Washington State constitutional right to privacy and therefore requires a search warrant). For a discussion of GPS evidence admissibility, see Schumann, *supra* note 37.

^{54.} Schumann, *supra* note 37, at 61 ("A property owner will always have the right to monitor the location of his or her property").

though some commentators speculate that "[t]racks of third parties, or of their property, without their knowledge are probably inadmissible and even illegal." The basis for this assertion is antistalking laws, sa tracking someone, be it through conventional means or GPS technology, is of course unlawful.

That said, antistalking provisions, while certainly helpful in some cases, are not necessarily relevant when GPS is used as an *assistive* technology in the health care context, particularly in cases of dementia. Beyond the obviously nefarious social implications of exposing caregivers to criminal liability, these laws are substantively inapplicable; antistalking laws require an element of reasonable fear on the part of the victim⁵⁸ and malice on the part of the actor,⁵⁹ both of which are lacking and irrelevant in the context of caring for dementia patients. Quite clearly, those who care for dementia sufferers in both an institutional and domiciliary context are not likely to be charged under such laws for attempting to prevent wandering—nor, of course, should they be.

Likewise, similar logic would preclude patients, or more likely their legal guardians or substitute decision makers, from availing

^{55.} Id. at 10.

^{56.} E.g., Wis. Stat. § 940.32 (2005) (including monitoring a victim by electronic means as a part of a stalking "course of conduct" that an actor "knows or should know" would cause the victim fear of bodily injury or serious emotional distress)

^{57.} See NAT'L INST. OF JUSTICE, U.S. DEP'T OF JUSTICE, PROJECT TO DEVELOP A MODEL ANTI-STALKING CODE FOR STATES 12 (1993); Lawrence M. Friedman, The One-Way Mirror: Law, Privacy, and the Media, 82 WASH. U. L.Q. 319, 329 (2004); B. Benjamin Haas, The Foundation and Visibility of Anti-Stalking Laws, 39 VILL. L. REV. 1387, 1387 & n.2 (1994); Nga B. Tran, A Comparative Look at Anti-Stalking Legislation in the United States and Japan, 26 HASTINGS INT'L & COMP. L. REV. 445, 445 (2003).

^{58.} NAT'L INST. OF JUSTICE, *supra* note 57, at 43–44 ("Any person who purposefully engages in a course of conduct directed at a specific person that would cause a reasonable person to fear bodily injury to himself or herself or a member of his or her immediate family or to fear the death of himself or herself or a member of his or her immediate family; and has knowledge or should have knowledge that the specific person will be placed in reasonable fear of bodily injury to himself or herself or a member of his or her immediate family or will be placed in reasonable fear of death of himself or herself or a member of his or her immediate family; and whose acts induce fear in the specific person of bodily injury to himself or herself or a member of his or her immediate family or induce fear in the specific person of the death of himself or herself or a member of his or her immediate family; is guilty of stalking.").

guilty of stalking."). 59. Fla. Stat. Ann. § 784.048(2) (West 2000) (defining a stalker as any person who "maliciously . . . follows or harasses another person").

Number 2 GPS Patient Tracking: An Ethical Dilemma 399

themselves of tort remedies against a monitoring caregiver;⁶⁰ the person doing the monitoring is most often the legal guardian himself.⁶¹ Instead, the current situation is best characterized as a virtual legal vacuum.

B. A Tendency to Trivialize: Why the Legal Limbo?

The already disquieting issue of elder neglect and abuse is further compounded by the advent of new technologies, which, while destined to improve the lives of those most at risk, raise new questions pertaining to their basic human rights of privacy and dignity. However important these issues may be, they nevertheless have gone

^{60.} See Timothy Joseph Duva, You Get What You Pay for and So Does the Government: How Law Enforcement Can Use Your Personal Property to Track Your Movements, 6 N.C. J.L. & TECH. 165, 178-79 (2004); Waseem Karim, The Privacy Implications of Personal Locators: Why You Should Think Twice Before Voluntarily Availing Yourself to GPS Monitoring, 14 WASH. U. J.L. & POL'Y 485, 511 (2004). The Second Restatement of Torts recognizes four privacy torts. RESTATEMENT (SECOND) OF TORTS § 652. For the purposes of tracking devices, the torts for unreasonable intrusion upon the seclusion of another and for dissemination of an individual's private information are applicable. Id. § 652A(2)(a), (c). If an individual wearing a personal locator whose information was sold to a third party were to seek a claim due to public dispersion of information regarding his private life, he must show that the matter publicized was of a kind that "would be highly offensive to a reasonable person" and that the information was "not of legitimate concern to the public." Id. § 652D. However, under this tort, a person cannot recover damages when he is in the public eye, as the intrusion does not pertain to his private life. Id. For liability to exist under the intentional intrusion of privacy tort, there must be an intentional intrusion "upon the solitude or seclusion of another," and the intrusion must be of a kind that is "highly offensive to a reasonable person." Id. § 652B. Because the tort involves an individual's solitude, liability generally does not exist when the individual is in the public eye. Id. § 652B cmt. c. However, solitude is not dependant upon whether the location is private, but rather upon the expectation of privacy and the kind of invasion that takes place. Id. § 652B cmt. b. Of all the privacy torts, the intrusion upon seclusion tort could most easily be applied in the GPS context. This tort is available against a person who intrudes on the solitude or seclusion of another if the intrusion would be highly offensive to a reasonable person. Id. § 652B. This intrusion need not be physical, but would include any intrusion, such as eavesdropping, onto an individual's private concerns. *Id.* § 652B cmt. c. Thus, it seems at first blush that if a company with positioning information released a user's information to a third party without consumer consent, the consumer would have a possible cause of action. The intrusion upon seclusion tort is also limited, however. Suits rarely succeed if the information has been gathered in a public space. *Id.* § 652B cmt. c. Thus, as with the disclosure of personal facts tort, "there is no liability for giving further publicity to what the plaintiff himself leaves open to the public eye." *Id.* § 652D cmt. b.

^{61.} This is an identity of interests problem. The term "identity of interests" refers to situations when the interests and wishes of the dementia sufferer coincide with those of his or her caregiver. In contrast, the interests of dementia sufferers and their caregivers may diverge with respect to the wisdom of monitoring.

unaddressed by the legal community, 62 as the commercial success and expediency of assistive technologies obstructs debate. The virtual vacuum surrounding the ethics of saddling the elderly with certain technological devices, even when the devices are ostensibly assistive, is itself a product of our collective neglect of elder rights and of budgetary health care constraints. 63

The general questions that need to be posed, but are habitually left unheeded, are the following:

On what grounds can we justify overriding and restricting the liberty of a person with dementia? How far should such restrictions go? Who should authorize them, and who should carry them out and under what theory? Given that all behavior carries some degree of risk, what level of risk is acceptable?⁶⁴

Finally, what implications might the mechanical application of assistive technologies have for liability and insurance purposes?

Why then are such questions left unasked? Several more specific reasons may be cited. First, as noted, the "threat" to the rights at stake generally stems not from government actors or malicious stalkers, but from those who care most for the elderly—family and caregivers who avail themselves of the assistive technology. Accordingly, even though several constitutional rights may be at issue, the traditional concept that human rights abuses are at the hands of state actors, coupled with the understandable reticence toward exacerbating the already weighty burden shouldered by caregivers, all but precludes such analysis. 66

Yet another reason underlying the difficulty in addressing elder rights in this context is that concrete interests relating to physical health or safety—particularly as they inhere to older people—are

^{62.} See Alzheimer's Soc'y, supra note 2.

^{63.} As noted above, this ties into the general issue of health care rights, which exceeds the specific parameters of this present discussion.

^{64.} Jennings, supra note 46, at 593.

^{65.} Cf. Carolyn Said, Old Age in the Technology Age: New Devices to Monitor Health and Well-Being at Home a Growing New Sector, S.F. CHRON., Aug. 8, 2005, at E-1, available at http://sfgate.com/cgi-bin/article.cgi?file=/c/a/2005/08/08/BUG7PE2HL01.DTL (discussing new technology, such as "granny-cams" used by middle-aged children to monitor their elderly parents); Press Release, SiRF, Wherify Wireless and SiRF Team to Deliver Child Locator System: Wherify Wireless Personal Location System Uses SiRF's GPS-enabled Location Technology to Help Locate Loved Ones (Mar. 19, 2001), http://www.sirf.com/mar19_2.html (describing GPS locator technology marketed towards middle-aged children caring for elderly parents).

^{66.} As noted, the criminal law would of course be inappropriate, thus leaving us in a legal vacuum. *See supra* text accompanying note 58.

ELTIS.DOC 1/20/2006 11:35:22 AM

Number 2 GPS Patient Tracking: An Ethical Dilemma 401

typically perceived to overshadow all other issues, including "abstract" rights such as dignity and privacy. Thus, it is deemed only natural for the frail to prioritize health at the expense of other intangible interests, including certain basic rights, that are characterized as "luxuries" that those in poor health simply cannot afford. Lastly, definitional qualms respecting how this new assistive technology should be labeled further complicate the issue.⁶⁷

The question then arises, what rights should be sacrificed for the patient's own good? First, the availability of various technological devices adapted to the health care market raise delicate quandaries that derive not from those bearing the elderly ill will, but from the most well-intentioned caregivers. Thus, violations of basic rights, when they do occur in this context, are the most insidious, for they stem not from disregard, but from overreactive and paternalistic concern. What is more, because it is private actors rather than the state that are potentially infringing on civil liberties, fewer remedies are available. Moreover, those that are available are, of course, not invoked. This is all the more true when the private actors in question are health care professionals or even loving family members.

Accordingly, an adversarial conception of rights predicated on and limited to the individual appears ill suited to a fruitful exploration of intrusive elder monitoring when such surveillance is carried out by loved ones. Instead, in this context the conventional individualistic model may best be replaced by the "idea of rights in relationship," as advanced by scholars such as Gilligan, Minow, Nedelsky, and Schneider.⁷⁰ Hence, dementia sufferers are not the autonomous⁷¹

67. See Ashcroft-Simpson, *supra* note 15, at 80, for a brief discussion of whether tagging and tracking constitutes "restraints."

^{68.} The Ethics and Humanities Subcommittee of the American Academy of Neurology reminds physicians of the importance of trying to maintain the patient's ability to participate in decisions about care: "Neurologists may unintentionally depersonalize demented patients because subconsciously they may equate the loss of intellect with the loss of personhood Neurologists should optimize the therapeutic benefit of the patient-physician relationship by striving to maintain respect for the patient and recognizing and avoiding depersonalization behavior." Am. Acad. of Neurology, Ethics & Humanities Subcomm., Ethical Issues in the Management of the Demented Patient, 46 NEUROLOGY 1180, 1180–83 (1996).

^{69.} See supra note 60.

^{70.} See Angela Campbell, Stretching the Limits of "Rights Talk": Securing Health Care Entitlements for Children, 27 VT. L. REV. 399, 407 (2003) ("Rather than portraying rights-bearers as autonomous individuals with competing interests, they constructed a framework that reflects our needs and capacities and entwines these factors through a network of social relations."); Jennifer Nedelsky, Reconceiving Rights as Relationship, 1 REV. CONST. STUD. 1, 11–13 (1993) (asserting that the notion of in-

individuals envisioned by the conventional approach, nor are their interests divorced from, or competing with, those of their caregivers. Rather, they are most often quite dependent on both health professionals and family members, thus rendering the traditional rights paradigm as unsuitable⁷² as any other enumerated private law remedies normally available.⁷³ Perhaps Edward P. Richards best summarizes the quandary, asserting: "Alzheimer's disease raises significant legal issues because it challenges our model of a world neatly divided into autonomous citizens and persons legally adjudged incompetent

dividual is flawed, since humanity is comprised of a network of relationships, and individuals are shaped and influenced in their choices by those relationships); Elizabeth M. Schneider. *The Dialectic of Rights and Politics: Perspectives from the Women's Movement*, 61 N.Y.U. L. REV. 589, 597–98 (1986) (arguing that feminist rights critique, which is based on patriarchy, fails to consider the "relationship between the assertion of rights and political struggle in social movement practice"); *id.* at 619–25 (discussing how feminist thought evolved to center around the notion of "interdependent rights").

71. In context of children (as there are many important parallels between children and the aged in terms of vulnerability, dependence, and the use of similar legal standards), "the traditional understanding of rights presumes an autonomous rights-holder, who is able to independently recognize and exercise her legal claims." Campbell surga note 70, at 400.

claims." Campbell, *supra* note 70, at 400.

72. *Id.* Again, the dependence parallel with children's rights is elucidating. As Campbell points out:

On an even more basic level, characterizing children's health care as a right creates two dilemmas that can arise whenever a rights-based discourse is employed. First, . . . this paradigm does not fit the context of children's rights for many of the same reasons that feminists reject the idea for women. The immense physical, emotional, and psychological dependence children have on their families, their communities, and the state, makes placing them within the traditional rubric of individual rights impossible. The notion of rights in relationship—a concept formulated and developed by feminists—thus becomes indispensable to a viable framework of rights for children.

Campbell, *supra* note 70. For an actual discussion of the parallels between elder's and children's rights, see Nina A. Kohn, *Second Childhood: What Child Protection Systems Can Teach Elder Protection Systems*, 14.1 STAN. L. & POL'Y REV. 175, 176 (2003) ("Looking to systems designed to address child maltreatment to reduce elder mistreatment is not new. Health care workers and policy makers have long considered elder mistreatment to be analogous to child maltreatment. When arguing that more attention should be paid to elder abuse, both groups have cited America's approach to child maltreatment as superior. This has had a significant effect on elder care policies. For example, elder protective services are frequently patterned on child protective services."). For more specific parallels on point with older children, see Devanshi P. Patel, *Should Teenagers Get Lolacked Against Their Will? An Argument for the Ratification of the United Nations Convention on the Rights of the Child*, 47 How. L.J. 429 (2004).

73. This is often due to the identity of interests problem previously discussed. *See supra* note 61.

and under the control of duly-appointed legal representatives in secure facilities."⁷⁴

More specifically, the conventional legal framework, in place to provide those lacking either competence or capacity with some recourse when their civil liberties are at stake, is usually the "best interests" test. ⁷⁵ While it is beyond the scope of this article to examine this generally problematic standard in any detail, ⁷⁶ the particular challenge to that standard when it comes to dementia patients is that anything serving to safeguard their physical integrity is traditionally understood as being in their best interests. Thus, while it is agreed that one's interests normally extend beyond the physical or health-related, that same logic rarely extends to the aged or dementia sufferers who are presumed to value their precarious health above all else. ⁷⁷

Such an approach may be consistent with a utilitarian construct. This would presumably favor the use of GPS technology by virtue of its supposed life-saving potential,⁷⁸ which outweighs the potential limitations on certain rights. It does not, however, comport with the rights-based philosophy that has come to dominate our understanding of health policy. A fundamental principle animating health care ethics is the respect for human dignity.⁷⁹ Indeed, the heightened emphasis on patient autonomy and dignity as overarching considerations permeates the law.⁸⁰ The same is true for determining incapac-

^{74.} Edward P. Richards, Public Policy Implications of Liability Regimes for Injuries Caused by Persons with Alzheimer's Disease, 35 GA. L. REV. 621, 622 (2001).

^{75.} See Cara D. Watts, Asking Adolescents: Does a Mature Minor Have a Right to Participate in Health Care Decisions?, 16 HASTINGS WOMEN'S L.J. 221, 242–43.

^{76.} Scholars have spilled much ink regarding the difficulties associated with the "best interests" standard, particularly in the family law context (though it lacks examination in its application to elders). See, e.g., Shauna Van Praagh, Faith Belonging and the Protection of "Our" Children, 17 WINDSOR Y.B. ACCESS TO JUST. 154 (1999); Shauna Van Praagh, Religion, Custody and a Child's Identities, 35 OSGOODE HALL L.J. 309 (1997); C. Bernard, R. Ward & B.M. Knoppers, Best Interests of the Child Exposed: A Portrait of Quebec Custody and Protection Law, 11 CAN. J. FAM. L. 57 (1992).

^{77.} As noted above, some interesting parallels with children's rights are worthy of further exploration. Dementia and old age has been referred to as a "second childhood." *See* Jane Spencer, *Tracking the Kids by Satellite*, WALL St. J., Feb. 18, 2003, at D1.

^{78.} It may also have the capacity to alleviate caregivers' worry. See id.

^{79.} Dignity regardless of autonomy is espoused by most health care professionals' codes of ethics. *See* AM. MED. ASS'N CODE OF MED. ETHICS (Council on Ethical and Judicial Affairs 2005); *see also* http://www.ama-assn.org/ama/pub/category/2498.html (last visited Sept. 18, 2005).

^{80.} See 3 JOEL FEINBERG, HARM TO SELF 4-5, 23, 27 (1986).

ity. 81 Physicians have an obligation to prevent harm, as does the state in some countries.82 While the precise definition of what constitutes harm remains the subject of great controversy, 83 particularly with assisted suicide, the concept clearly exceeds physical injury.⁸⁴

The elderly should be no exception. The elderly—including those suffering from Alzheimer's or other dementia—are likewise entitled to the equal protection of interests other than physical health, including dignity and privacy.85 Tom Kitwood, a leading Alzheimer's medical researcher, once cautioned that personhood and the inalienable rights intrinsic to it are not supplanted by age-related illness and the pragmatic health care considerations that accompany it, despite the tragic loss of autonomy from dementia. 86 As he so eloquently stated, "[t]he unifying theme is the personhood of men and women who have dementia—an issue that was grossly neglected for many years both in psychiatry and care practice."87

Thus, for instance, nonmedical interests must be thought to survive dementia and age, as a leading researcher, Susan Dodds, empha-

^{81.} See id. at 316.

^{82.} See generally Bundesverfassungsgericht [BVerfG] [Federal Constitutional Court] May 28, 1993, 88 Entscheidungen des Bundesverfassungsgerichts [BVerfGe] 203 (F.R.G.) (upholding the criminalization of abortion on the basis of the State's constitutional duty to protect life).

^{83.} See, e.g., 42 U.S.C.A. § 13031 (West 1995) (defining "harm" in child abuse as physical or nonphysical injury, sexual abuse, negligent treatment and the failure to provide food, shelter or medical care); FLA. STAT. ANN. § 39.01(f) (West 2003) (defining "harm" to a child's welfare which eliminates requirement of spiritual healing accommodations); King v. King, 828 S.W.2d 630 (Ky. 1992) (vaguely defining "harm" to the child in the context of grandparents visitation rights), cert. denied, 506 U.S. 941 (1992); see also Adam Fraser, Protected from Their Own Beliefs: Religious Objectors and Paternalistic Laws, 18 BYU J. Pub. L. Rev. 185, 189-92 (2003) (distinguishing between spiritual and secular harms and arguing that individuals should be exempt from secular laws which violate religious beliefs); Ann Hubbard, Meaningful Lives and Major Activities, 55 ALA. L. REV. 997, 1020 (2004) (arguing that the definition of serious harm is "the significant impairment of an individual's social participation"); Eileen L. McDonagh, My Body, My Consent: Securing Constitutional Consent for Abortion Funding, 62 ALB. L. REV. 1057, 1069 (1999) (arguing that "[T]he legal definition of harm rests upon the right of a person to consent

to what is done to her/his body and liberty").

84. See, e.g., King, 828 S.W.2d at 632 (discussing harm to grandchildren when the grandparent is denied visitation rights), cert. denied, 506 U.S. 941 (1992); see also Hubbard, supra note 83, at 1020.

See Christine A. Clark, Review of Florida Legislation: Religious Accommodation and Criminal Liability, 17 FLA. ST. U. L. REV. 559, 584-85 (1990).

^{86.} TOM KITWOOD, DEMENTIA RECONSIDERED: THE PERSON COMES FIRST 27 (1997) (revisiting the psychological needs of people with dementia: i.e., love and dignity, which are not simply physical).

^{87.} Id. at 55.

NUMBER 2 GPS PATIENT TRACKING: AN ETHICAL DILEMMA 405

sizes: "[t]here is no reason to believe that as people become older and less able to live fully independently they lose all interests beyond the protection of their health."88

While medical interests may indeed be fundamental for some elders in poor health, it is important not to casually *assume* that this is always the case simply by reason of their age or condition. Such a "broad brush approach" is, as Bruce Jennings defines it, "objectionable" and indeed discriminatory.⁸⁹ Jennings proceeds to remark:

[a]nother aspect of the public health framework that makes it problematic in application to risky behavior by Alzheimer's disease patients is the tendency to view persons categorically rather than situationally. Dealing as it does with large populations, statistical risks, and impersonal factors, public health policy often deals with broad categories, particularly in its surveillance and reporting functions.⁹⁰

Preferences amongst dementia sufferers will vary as a function of several factors, including cognitive ability, culture, and idiosyncratic differences.⁹¹ These cannot be dismissed and must instead be acknowledged: "With Alzheimer's disease specifically, the degenerative processes of the disease operate in often very subtle and uneven ways with respect to cognitive and reasoning functions." The same author speaks of degrees of "cultural competence" that must similarly be accounted for. Plainly put, "[c]urtailing freedom always calls

^{88.} Susan Dodds, Exercising Restraint: Autonomy, Welfare and Elderly Patients, 22 J. Med. Ethics 160, 162 (1996).

^{89.} Jennings, *supra* note 46, at 602. With respect to driving, Edward P. Richards notes that "it would be difficult to justify blanket rules that prohibit all persons diagnosed with Alzheimer's disease from driving because such rules would improperly limit the lives of a large number of persons who do not yet pose any threat to others." Richards, *supra* note 74, at 625.

^{90.} Jennings, *supra* note 46, at 602.

^{91.} Ramón Valle, Ethics, Ethnicity, and Dementia: A "Culture Fair" Approach to Bioethical Advocacy in Dementing Illness, 35 GA. L. REV. 465 (2001) (citing Linda Farber Post et al., Pain: Ethics, Culture, and Informed Consent to Relief, 24 J. L. MED. & ETHICS 348, 355 (1996)).

^{92.} Valle, *supra* note 91, at 476.

^{93.} *Id.* The degree to which the psychiatric patient's bodily integrity is protected by the right to refuse treatment turns on whether the patient is found to have the capacity to make such a decision. Most jurisdictions prefer what is known as a "functional" approach to capacity. Thus, for instance, in Quebec law, the determination of capacity to consent to treatment is a question of fact and is based on the patient's ability to make the decision at hand. *See generally* [1994] R.J.Q. 2523 (C.A.). "Il peut fort bien arriver qu'une personne soit incapable d'administrer ses biens, tout en étant parfaitement consciente de ses besoins de santé." (It can very well be the case that a person who is incapable of administering their property would otherwise be fully aware of their health needs.) *Id.* at 2529.

for legal justification, and an Alzheimer['s] diagnosis is in itself insufficient to furnish it." Moreover, "the primary duty of the conservator vis-à-vis the person with Alzheimer's disease is not so much protection from bodily harm, nor the promotion of best interests, at least as that term is commonly understood. Instead, the goal of conservancy is, simply put, to sustain the person's human flourishing or quality of life as a person." ⁹⁵

Therefore, in applying the "best interests" test, we must separate ourselves from any notion that the elderly have lost interest in concerns beyond their physical well-being. It is perhaps worth reiterating that nonphysical harms potentially attributable to the use of assistive technology involving GPS monitoring include the stigma and humiliation (in moments of lucidity) that ensue from being tagged and tracked. Indeed, beyond the stigma, actually being tagged may reflect on the social value attributed to the group. The elderly already suffer from low self-esteem in Western culture, as evidenced by high rates of suicide amongst that group. Being tagged can only exacerbate this situation.

IV. Our "Best Interests" or Theirs?

What makes the matter all the more difficult is that tagging, at first glance, appears to be a practical means for preventing the potential physical harm from wandering in those suffering from dementia. This technology's potential for offering some solace to those whose every minute is filled with fear that a patient under their care will disappear only to be found dead cannot be overlooked.

What is disturbing and requires additional debate, rather than mechanical approval, is that overburdened, underfunded caregivers may understandably be tempted to attach undue weight to the technology's ability to alleviate their burden, as opposed to the patient's intangible rights, thus giving it a rubber stamp of approval. Under-

^{94.} Bruce Jennings, *A Life Greater Than the Sum of Its Sensations: Ethics, Dementia, and the Quality of Life, in Assessing Quality of Life in Alzheimer's Disease 165 (Steven M. Albert & Rebecca G. Logsdon eds., 2000).*

^{95.} Id.

^{96.} See Ashcroft-Simpson, supra note 15, at 83–84.

^{97.} See Nat'l Strategy for Suicide Prevention, At a Glance—Suicide Among the Elderly, http://www.mentalhealth.org/suicideprevention/elderly.asp (last visited Sept. 18, 2005). The highest suicide rates of any age group occur among persons aged sixty-five years and older. See also Inst. on Aging, http://ioaging.org/programs/cesp/sfacts.html (last visited Sept. 18, 2005).

standably, "carers like the idea of electronic tracking devices if these can ensure that the wanderer is found more swiftly." Of course, caretakers' best interests and those of their patients, though not inseparable, are intimately linked and therefore must be soberly considered. 99

A. Beyond Rights

Balance, needless to say, is of the essence. Mental health professionals have accused attorneys of focusing only on legal rights and ignoring treatment concerns, thus allowing their clients to "rot with their rights on."100 Beyond rights, however, arise practical considerations, or considerations relating to a patient's psychological wellbeing, that also must be properly weighed prior to approving invasive assistive technologies like GPS. Thus, for instance, "[f]or some dementia patients, any diversion from their ordinary routine, even to undergo a procedure that to an ordinary person would seem minor, can 'constitute real threats to needed order and stability, contribute to already high levels of frustration and confusion, or result in a variety of health complications."101 Ultimately, in the dementia context, Rebecca Dresser argues that "[f]or life-sustaining treatment to be appropriate, it must confer a substantial enough benefit to outweigh both its customary risks and the distinctive experimental burdens it poses for dementia patients unable to fathom its purpose." Proportionality is key.

Revisiting the nexus between carers and patients, this technology may have the additional disadvantage of creating a false sense of security among caregivers, thus potentially fostering greater complacency in care or human surveillance; there may be a tendency to leave

^{98.} Hughes & Louw, *supra* note 27, at 848 (citing Rupert McShane et al., *The Feasibility of Electronic Tracking Devices in Dementia: A Telephone Survey and Case Series*, 13 INT'L J. GERIATRIC PSYCHIATRY 556 (1998)).

^{99.} See supra note 61.

^{100.} See Dennis E. Cichon, The Right to "Just Say No": A History and Analysis of the Right to Refuse Antipsychotic Drugs, 53 LA. L. REV. 283, 320 & n.4 (1992). That is why input of other professions is so essential.

^{101.} Penney Lewis, Procedures That Are Against the Medical Interests of Incompetent Adults, 22 Oxford J. Legal Stud. 575, 609 (2002) (citing E. Keyserlingk et al., Proposed Guidelines for the Participation of Persons with Dementia as Research Subjects, 38 Persp. In Biology & Med. 319, 324 (1995)).

^{102.} Rebecca Dresser & Peter J. Whitehouse, *The Incompetent Patient on the Slippery Slope*, HASTINGS CENTER REP., July–Aug. 1994, at 6, 10.

it to the machines. Osme support for this premise may be found in studies which, though unsophisticated, point to decreased alertness accompanying the benefit of decreased stress: [e]vidence from small unsophisticated studies comparing events or attitudes before and after the installation of boundary alarms shows that such systems are effective and can decrease stress in carers and patients. Moreover, these devices are not foolproof, as illustrated by the following incident: One patient was injured by a passing vehicle when he had got lost out of range of the device. 105

Finally, although the use of GPS tagging and tracking of Alzheimer's and dementia patients may first appear to curtail costs associated with insurance and liability, if it becomes routine, as noted, caregivers may ultimately be exposed to greater costs if they find themselves caring for patients competent enough to refuse tagging (either at the time or via advanced directives, as noted below). Will liability follow caregivers that fail to undertake GPS tagging as a 'reasonable precaution' even in situations where the patient refuses such monitoring? Taken to the extreme, will those who decline GPS be denied insurance or care, particularly by profit-seeking managed care facilities?

To address these delicate issues, a courageous policy review is in order. Such policies would require the health benefits of assistive technologies to be shown to outweigh other interests in accordance with the principle of equality. In the words of Isaiah Berlin:

The assumption is that equality needs no reasons, only inequality does...; that uniformity, regularity, similarity, [and] symmetry...need not be specially accounted for, whereas differences, unsystematic behavior, [and] change in conduct, need explanation and, as a rule, justification. If I have a cake and there are ten persons among whom I wish to divide it, then if I give exactly one tenth to each, this will not... call for justification; whereas if I de-

^{103.} Welsh et al., *supra* note 14, at 372 ("[T]hey cite increased opportunity for abuse through, for example, the withdrawal of staff and financial resources from the care of people with complex needs. Implementing these technologies, therefore, has ethical implications for human rights and civil liberties.").

^{104.} Hughes & Louw, *supra* note 27, at 848 (citing Peter Blackburn, *Freedom to Wander*, NURSING TIMES, Dec. 7, 1998, at 54–55).

^{105.} Rupert McShane et al., supra note 98, at 556.

^{106.} See infra Part V for additional discussion. Although it exceeds the parameters of this paper to go into the details of a caregiver's potential liability arising from harm caused by an Alzheimer's patient, an interesting discussion on one aspect can be found in Richards, *supra* note 74.

^{107.} See Nicholas P. Terry, An eHealth Diptych: The Impact of Privacy Regulation on Medical Error and Malpractice Litigation, 27 Am. J.L. & MED. 361 (2001).

NUMBER 2 GPS PATIENT TRACKING: AN ETHICAL DILEMMA 409

part from this principle of equal division I am expected to produce a special reason." $^{108}\,$

Lastly, definitional issues further complicate the matter. Whether electronic tagging is considered a form of restraint remains to be determined. 109

B. Expediency Versus Dignity

Americans' readiness to welcome assistive technologies arguably speaks to our desire for expediency or quick fixes to multifaceted issues. American culture places great importance on cost and public security. Electronic surveillance, needless to say, greatly facilitates these ends and therefore tends to be more readily accepted. As William G. Staples points out, we are creating a "culture of surveillance" by allowing devices and processes into our lives that serve to evaluate our conduct and actions and track our every move. 111

In the same vein, Bruce Jennings observes,

the ethical and legal traditions of the United States pose the ethical dilemma as a conflict of two important principles or values—individual liberty versus prevention of harm to others, or public safety. The United States' tradition seeks a solution to this dilemma in the notion of legitimate or authoritative protection. This involves protection of the individual from harming himself or herself and protection of others, especially those who may find themselves in harm's way. In this stage of Alzheimer's disease there seems little choice but to restrict individual liberty, perhaps quite severely, in order to protect public safety. 112

Presumably then, the importance allotted to public safety is rivaled only by that attached to cost. As Robert Koester, a neurobiologist at the University of Virginia and perhaps the leading researcher on Alzheimer's-related wandering, observes: "When you consider that a search for an Alzheimer's wanderer can cost thousands of dollars, you can understand why law enforcement agencies

^{108.} Isaiah Berlin, *Equality as an Ideal*, in JUSTICE AND SOCIAL POLICY 128, 131 (Frederick A. Olafson ed., 1961).

^{109.} Ashcroft-Simpson, supra note 15, at 80.

^{110.} See WILLIAM G. STAPLES, THE CULTURE OF SURVEILLANCE: DISCIPLINE AND SOCIAL CONTROL IN THE UNITED STATES 1–12 (Steve Debow ed., 1997).

^{111.} *Id*.

^{112.} Jennings, supra note 46, at 596.

^{113.} For a discussion of cost and insurance considerations in the American context, see Christine R. Kovach, *Alzheimer's Disease: Long-Term Care Issues*, 12 ISSUES L. & MED. 47 (1996); Mark A. Rothstein, *Predictive Genetic Testing for Alzheimer's Disease in Long-Term Care Insurance*, 35 GA. L. REV. 707 (2001).

want to use it."¹¹⁴ As highlighted above, law enforcement may not be the only agency seeking financial relief from the burden of elder care. Overworked, underfunded, and often overwhelmed health care workers or family members are in desperate search of relief. Even more so, for-profit managed care facilities are eager to unearth cost-cutting measures, such as GPS technology, which saves manpower costs by tracking patients.

The twin pillars of cost and safety that underlie the American approach to health care risk point society to quick fix solutions whose long-term price may outweigh their immediate benefits. While the use of assistive technology to further the objectives of promoting safety and saving costs should be encouraged, such measures should only follow sober reflection and profound cost-benefit analysis that exceeds simply financial cost or physical health benefits. As Susan Cahill warns, "[i]n dementia we need to move beyond quick fix practical solutions such as electronic tagging, which so often serve the needs of formal caregivers while eroding the rights of those with a cognitive impairment."

V. A Final Word

As shown, both conventional paradigms of rights, and traditional legal standards, such as the "best interests" tests, ¹¹⁶ fail to sufficiently address the intricate issues raised by assistive technologies in the dementia context. Instead, what can best be described as a virtual legal vacuum prevails, relegating some of society's most vulnerable to an unexamined fate, characterized by our propensity to embrace assistive technologies prior to fully investigating the ethical dilemmas that they generate.

In an effort to improve the current situation, this article aims at sparking meaningful multidisciplinary discussion on what appropriate safeguards may be developed—legislative or otherwise. Such a discussion is necessary to address the ethical issues related to elder monitoring and to ultimately foster a sensitive application of new as-

^{114.} Cynthia Kuhn, Ph.D. & Wilkie Wilson, Ph.D., 'Tagging' Alzheimer's Patients: Electronic Devices Deter Wandering Off, but at What Cost?, Web MD, http://aolsvc.health.webmd.aol.com/content/Article/52/50224.htm. (last visited Sept. 18, 2005).

^{115.} Cahill, supra note 27, at 282.

^{116.} See supra Part IV.

NUMBER 2 GPS PATIENT TRACKING: AN ETHICAL DILEMMA 411

sistive technologies in a manner that allows technology to promote dignity in dementia care. The first step is to actually *ask* some much-needed questions that increase understanding of the issues and allow for informed decision making.

While it is certainly beyond the scope of this article to propose any clear resolution of the predicament, the following points are suggested for reflection:

A. Advance Directives

In anticipation of a clearer and more permanent resolution, it may be helpful for those diagnosed with Alzheimer's (or in the early stages of other illnesses resulting in dementia)¹¹⁷ to avail themselves of advance directives;¹¹⁸ advance directives would allow them to express their wishes regarding the use of GPS technology to track them as their dementia progresses. Though not free of controversy,¹¹⁹ what Ronald Dworkin calls "precedent autonomy"¹²⁰ allows a now-capable person to control decision making at a later point in time when she no longer has the capacity to do so.¹²¹ Such precommitment¹²² would, at the very least, allow the patient to regain some authority over the use of new technologies to monitor her movements.¹²³ For instance,

117. "[D]iagnostic tests [have] developed that allow Alzheimer's disease to be diagnosed long before it affects behavior." Richards, *supra* note 74, at 624.

^{118.} The wishes of the patient are to be considered by the substitute decision maker at two stages under The Substitute Decisions Act: (1) in acting in accordance with a prior capable wish applicable to the circumstances; and (2) in determining the incapable person's best interests where there is no capable wish known or applicable to the circumstances. The Substitute Decisions Act, R.S.O., ch. 30, § 66(3) (1992).

^{119.} Rebecca Dresser refers to this as a quick fix. *See* Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 RUTGERS L. REV. 609, 635 (1994); *see also* ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING (1989).

^{120.} Ronald Dworkin, Autonomy and the Demented Self, 64 MILBANK Q. 4, 10 (Supp. 2, 1986).

^{121.} *Id.* at 13.

^{122.} For a more detailed discussion of living wills and precommitment (or advance directives), see Leslie Pickering Francis, *Decision Making at the End of Life: Patients with Alzheimer's or Other Dementias*; 35 GA. L. REV. 539 (2001). For a critique, see Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 Tex. L. REV. 1823 (2003).

^{123.} Nancy Neveloff Dubler, Creating and Supporting the Proxy Decision-Maker: The Lawyer Proxy Relationship, 35 GA. L. REV. 517, 535 (2001) ("I would suggest that there is a powerful lesson here for attorneys counseling patients who face the prospect of increasing dementia. The first lesson is that, if the patient has a trusted and loved person who can be appointed as a health care proxy agent, that is the much preferred sort of advance directive for the patient to execute. Especially in

ELTIS.DOC 1/20/2006 11:35:22 AM

412 The Elder Law Journal

VOLUME 13

[i]f the [legally] incompetent was previously competent, her earlier autonomous decisions regarding medical treatment can be projected into the future once she [is deemed] incompetent. Even if [those deemed] incompetent failed to make such advance decisions, her autonomy can be respected by making the decision that she would have made, based on evidence of her previously competent wishes, preferences and values. The best interests test is the key example of decision-making based on the protection of the incompetent's welfare interests, and it can be used regardless of whether the incompetent was previously competent. 124

Having said this, advance directives are nevertheless no more than ad hoc solutions. As noted, other considerations such as insurance and institutional liability¹²⁵ or even family pressure¹²⁶ may make advance directives superfluous if use of these technologies becomes routine.¹²⁷ For this reason, this author supports British scholars Hughes and Louw's call for government supervision of the application of GPS surveillance technologies to dementia sufferers and others. Their suggestion to secure legislation that regulates collection of personal data through GPS devices generally, and surveillance of vulnerable groups such as the aged or children specifically, is an urgent call for action meriting immediate attention here as well.

In light of the above, assistive technology should only be made available "in circumstances where it offers immediate therapeutic benefits of proven efficacy as well as a positive benefit-risk ratio." ¹²⁸ In this vein, one author, dealing with GPS surveillance generally, has suggested that a model privacy law should "regulate the collection and use of personal data with [both] implantable [and] nonimplantable [GPS] chips. Such a statute should legislate inalienabilities that place use-transfer restrictions on the personal information generated through wearable GPS devices." That article's author, Paul M.

dementia, where cognitive decline can proceed far more quickly than physical deterioration, the existence of a proxy to weigh possible interventions against past wishes and present situation is critical.").

^{124.} Penney Lewis, Procedures That Are Against the Medical Interests of Incompetent Adults, 22 OXFORD J. LEGAL STUD. 575, 578 (2002).

^{125.} See supra notes 34–35, 60 and accompanying text.

^{126.} This technology allots family members and caregivers more convenience generally.

^{127.} See supra notes 34–35, 60 and accompanying text.

^{128.} Patrik S. Florencio, Genetics, Parenting, and Children's Rights in the Twenty-First Century, 45 MCGILL L. J. 527, 557 (2000).

^{129.} Paul M. Schwartz, *Property, Privacy and Personal Data*, 117 HARV. L. REV. 2055, 2119 (2004) (citing Margaret Jane Radin, *Humans, Computers, and Binding Commitment*, 75 IND. L.J. 1125, 1159, 1161 (2000) (objecting to any "waiver of all per-

NUMBER 2 GPS PATIENT TRACKING: AN ETHICAL DILEMMA 413

Schwartz, further called for institutions to "police the privacy promises and practices of wearable chip companies. Institutions are necessary to provide trading mechanisms to help with verification of interests in propertized personal data, and to enforce compliance with agreed-upon terms and legislatively mandated safeguards." ¹³⁰

B. Changing Our View of Consent: Making a Reasonable Versus a Rational Choice

The dominant approach toward the evaluation of decisionmaking capacity emphasizes cognition and rationality.¹³¹ Berghmans and Widdershoven note, has "some serious shortcomings,"132 as other relevant considerations such as feelings and emotions are set aside. 133 While a thorough discussion of consent exceeds the scope of this article, it suffices to note that focusing on rationality has the potential for depriving Alzheimer's patients still capable of making decisions of accepting or rejecting tagging and tracking. Especially in light of the fact that "[a] decision sometimes is considered irrational merely because the patient's choice was unconventional."134 Placing dignity above convenience or even health concerns may not always be rational, but it can certainly be reasonable. Consequently, emotions and intangible considerations should be taken into account when assessing decision-making capacity, particularly as it pertains to tagging and tracking in the dementia context. This would allow dementia sufferers, who are most commonly Alzheimer's patients, to enjoy the option of choosing dignity over physical security and thereby respect the elderly's multiplicity of interests.

sonal privacy rights" and calling on policy makers to exclude such a decision "on autonomy grounds")).

^{130.} Id. at 2120.

^{131.} Ron L.P. Berghmans & Guy A.M. Widdershoven, *Ethical Perspectives on Decision-Making Capacity and Consent for Treatment and Research*, 22 MED & L. 391, 394 (2003).

^{132.} *Id.* at 391.

^{133.} *Id.* at 398–99 ("The relevance of mood and emotion to decision-making capacity has not received much attention in the literature. If emotion receives any attention at all, generally this concerns the negative impact of emotions on decisional capacity. Leaving affective and emotive aspects outside of the process of capacity assessment and focusing on cognitive abilities may unjustifiably deny some patients their right to participate in decision-making.").

^{134.} *Id.* at 397.

VOLUME 13

C. Part of a Greater Health Care Problem

While legislation specifically pertaining to the use of GPS technology for surveillance of vulnerables is of the essence, we must nevertheless remain mindful of the fact that this specific question cannot be separated from the greater issue of health care rights. Indeed, other English scholars argue that the answer lies not in legislation, but in addressing the root causes leading to the temptation to resort to such quick fixes. The answer they put forward is to be found in "adequate funding of services to the population with dementia across the myriad of living situations." In other words, "if home care were supported properly[,] the use of these devices could be lessened. If nursing homes were at all adequately staffed and funded[,] perhaps they could be eliminated altogether." 137

Certainly, inadequate funding of institutions and support for domiciliary care, limited resources, and the desperate need for relief from the overwhelming burden placed on caregivers can only lead to a temptation to reflexively resort to technology that offers the promise of reprieve. In consequence, facilitating carers' lives, particularly that of home caregivers, would help render this technology a redundant last resort.

That having been said, as a second generation right, the right to health care, although cardinal, ¹³⁸ has often been more difficultly recognized (as compared to first generation individualistic rights). ¹³⁹ Ironically, legislation ensuring the protection of conventional rights such as privacy and dignity may be more readily achieved than any hope of addressing the underlying problems plaguing the health care system. ¹⁴⁰ We must therefore not rely on the resolution of these un-

^{135.} Cahill, supra note 27, at 282.

^{136.} Kevin D. Bail, Letter to the Editor, *Devices May Be Preferable to Locked Doors*, 326 BRIT. MED. J. 281, 281 (2003) (responding to Julian C. Hughes & Stephen J. Louw, *Electronic Tagging of People with Dementia Who Wander*, 325 BRIT. MED. J., 847, 847–48 (2002)).

^{137.} Id.

^{138.} See Dworkin, supra note 49, at 885.

^{139.} See LOUIS HENKIN ET AL., HUMAN RIGHTS 80–88 (1999), for more detailed analysis on point. *See also* Campbell, *supra* note 70, at 400 ("An additional difficulty with basing legal claims on rights is that rights impose a correlated obligation on other individuals, institutions, or the state.").

^{140.} See generally Marco Laverdière, Le cadre juridique canadien et québécois relatif au développement parallèle de services privés de santé et l'article 7 de la Charte canadienne des droits et libertés, 29 R.D.U.S.117 (1998–99) (discussing accessible health care as a charter right and the erosion thereof).

ELTIS.DOC 1/20/2006 11:35:22 AM

NUMBER 2 GPS PATIENT TRACKING: AN ETHICAL DILEMMA 415

derlying problems, however crucial they are, to address the GPS in dementia care conundrum.

As previously stated, the purpose of this article is not to offer precise recommendations. Indeed, doing so prior to and in the absence of multidisciplinary reflection would be premature. It is instead aimed to draw attention to what has thus far been a "low-profile" issue, ¹⁴¹ and to likewise ensure that any responses that are ultimately offered be informed by rights, ¹⁴² rather than by considerations relating exclusively to health. Discussion and debate is imperative if we are to increase awareness and understanding of the issues surrounding decision making regarding the use of assistive technologies.

VI. Conclusion

[T]he personal freedom of individuals, including those with a diagnosis of dementia, should be respected. Curtailing that freedom always requires ethical and legal justification. In general, the only justification for curtailing this freedom is to prevent harm to others or to the individual. Restrictions imposed for the protection of the individual from [self-inflicted harm] should be viewed with special caution [in order] to avoid over-inclusive applications of the concept of self-harm. ¹⁴³

^{141.} See Edward D. Spurgeon et al., Foreword: Joint Conference on Legal/Ethical Issues in the Progression of Dementia, 35 GA. L. REV. 391 (2001).

^{142.} Richard A. Ball, Legal Issues in Electronic Tagging of Offenders in the Home: Examples from the United States, 4 Y.B. OF L. COMPUTERS & TECH. 143, 155–56 (1990) ("One of the interesting aspects of the 'tagging' trend is the relative nonchalance with which it treats the question of the offender's body. This most personal of 'possessions' is treated as if it were fairly insignificant property of which the authorities can make pragmatic use under the circumstances. As for the tagged offender, he or she is expected to feel no significant sense of intrusion with respect to the tagging of this most personal 'property,' without which all other property would be not only useless but meaningless.").

^{143.} Recommendations of the Joint Conference on Legal/Ethical Issues in the Progression of Dementia, 35 GA. L. REV. 423, 428 (2001) (alteration in original).