
Ethical Considerations in the Conduct of Electronic Surveillance Research

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Nearly 2.5 million Americans currently reside in nursing homes and assisted living facilities in the United States, accounting for approximately five percent of persons sixty-five and older.¹ The aging of the “Baby Boomer” generation is expected to lead to an exponential growth in the need for some form of long-term care (LTC) for this segment of the population within the next twenty-five years. In light of these sobering demographic shifts, there is an urgency to address the profound concerns that exist about the quality-of-care (QoC) and quality-of-life (QoL) of this frailest segment of our population. The United States General Accounting Office (GAO) recently reported that,

One in five nursing homes nationwide (about 3,500 homes) had serious deficiencies that caused residents actual harm or placed them in immediate jeopardy...Moreover, GAO found significant understatement of care problems that should have been classified as actual harm or higher – serious avoidable pressure sores, severe weight loss, and multiple falls resulting in broken noses and other injuries...²

The GAO attributes the underreporting of such problems to: (a) lack of clarity regarding the definition of harm, (b) inadequate state supervisory review of surveys, (c) delays in timely investigation of complaints,

and (d) predictability of the timing of annual nursing home surveys. Equally importantly, without methods to continuously record, monitor and document the care of these residents, it is exceedingly difficult to verify resident-specific data reported by nursing homes and review complaint investigations. These tasks would be greatly aided by tools that enable accurate assessments of patient care and treatment.

Concerns about abuse and neglect of nursing home residents have led to the introduction of “granny cam” legislation in at least eleven states.³ Passage of the legislation, in any of its several permutations, would essentially permit families and legal representatives of nursing home residents to install video cameras in their loved one’s room to monitor their care. Proponents of “granny cams” have argued passionately that the scope and severity of the abuse and neglect problems warrant such intervention. Their opponents argue that such measures would unduly burden the LTC industry with unmanageable liability insurance costs, demoralize the already small and dwindling overburdened nursing home staff, and would not necessarily guarantee improved care any more than surveillance cameras at convenience markets have succeeded in curtailing crime.⁴ The ethical implications of surveillance technologies on the privacy and dignity of LTC residents, personnel and the care processes involved merit more systematic investigation.

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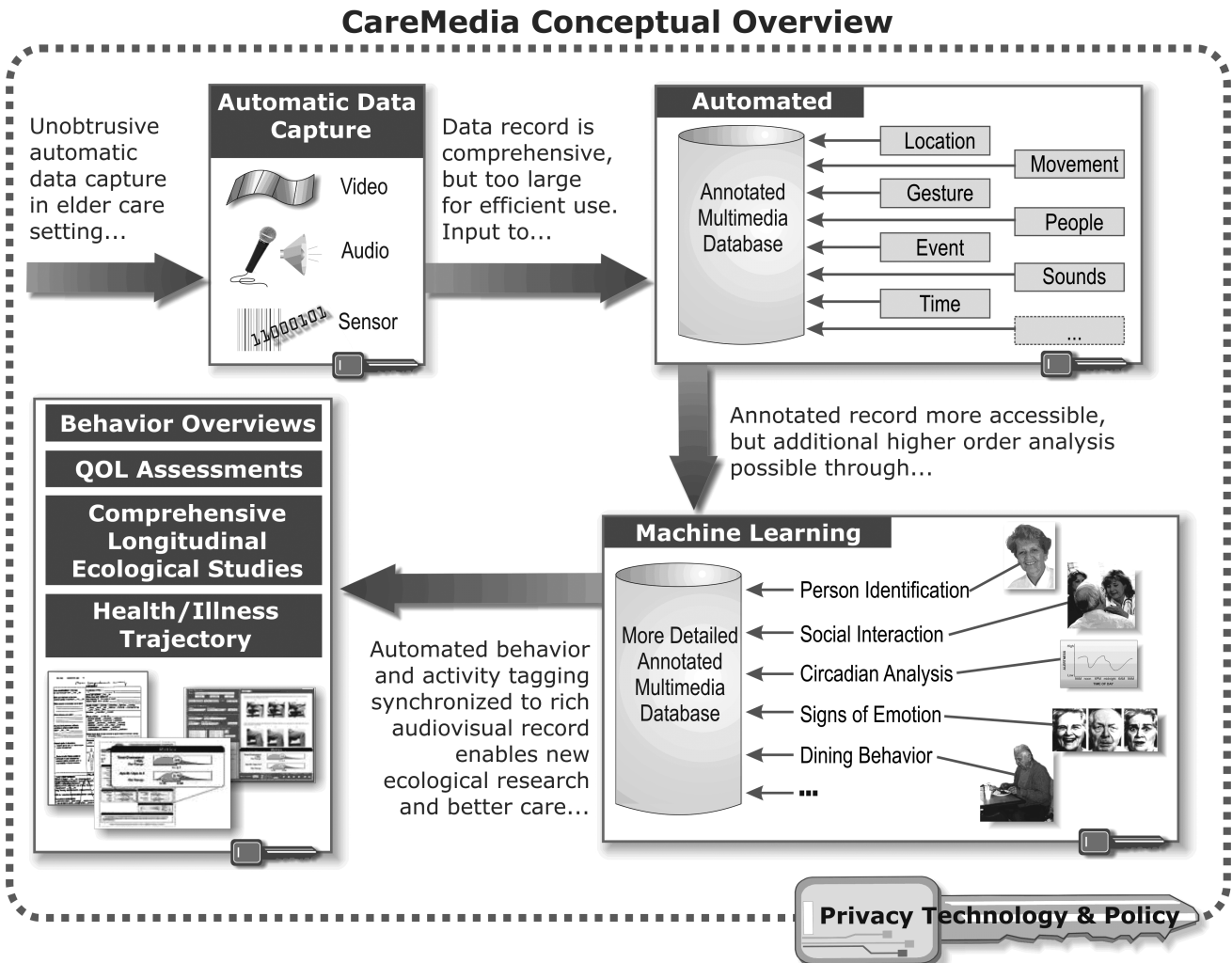
In contrast to “granny cams” which are installed in the *nursing home resident’s room*, the authors are attempting to record and analyze the lives of nursing home residents continuously in real-time in the shared spaces of community-based representative dementia units (hallways, activity and dining rooms) using video, audio and sensor technologies. *CareMedia: Automated Video and Sensor Analysis for Geriatric Care* (NSF 0205219) is a project that uses automated speech, image, and natural language processing to create a rich, indexed, searchable multimedia database in which salient episodes of resident care and functioning are captured and stored for future clinical evaluation (Figure 1).

Figure 1 Conceptual Overview of the CareMedia Project

Beginning with raw video, audio and sensor data captured via digital cameras, microphones, and sensors, human coders specify events of interest, such as falls,

punching or kicking. Based on the human coding, computer algorithms are developed to automatically detect the event and its contextual characteristics. In this manner, the computer is “trained” to detect salient events, eventually reducing the need for human data coding to only those circumstances that are phenomenologically and semantically challenging even for human eyes. Furthermore, irrelevant and redundant data can be reduced using techniques developed over the past decade that permit the analysis of large volumes of raw data that previously would have been prohibitive. Thus, this technology has the potential to record, analyze and document QoC and QoL in nursing home settings by:

- Augmenting qualitative observations with quantitative dimensions, transforming largely subjective assessments into more measured, objective ones.
- Enriching discrete, human observations with a machine-captured, continuous longitudinal re-



cord complete with automated analysis to detect and trace the trajectory of subtle changes in individual functioning.

- Detecting and annotating the possible antecedents and consequences of salient events (for example, falls).
- Refining and expanding existing methodologies for coding affect, behavior, and social interactions.
- Recording the “objective” environment to explore person-environment interactions unobtrusively.

However, the envisioned applications of CareMedia must be counterbalanced with the current limitations of the technology that include: (a) labor-intensive human coding of the digitally captured data, (b) refinement of machine learning algorithms as more “real world” data from LTC facilities become available to iteratively “train” the computers, (c) logistics and costs of implementing the technologies in residential care facilities, and most importantly, (d) the challenges of privacy and confidentiality protection of human subjects and procurement of informed consent from cognitively impaired LTC residents and/or their legally authorized representatives.

In this paper the authors describe the strategies employed to address serious ethical challenges encountered during the actual implementation of this project despite limiting the video and audio recordings to the shared spaces of nursing home dementia units. Specifically, we identify the stakeholders and their respective interests, the ethical challenges of conducting video/audio surveillance research with cognitively impaired subjects, and issues of privacy and confidentiality entailed by the recordings. We describe and discuss these challenges by systematically reviewing the difficulties encountered at each step of the project implementation.

Whose Rights are Under Consideration?

A broad sensible answer to this question is all persons with access to the locked dementia unit. However, the “rights” and interests of each stakeholder, while overlapping in some instances, are distinctly dependent on his/her role and responsibilities within the nursing home setting (see Table 1). Clearly, no one right applies equally to all persons at all times, but each individual must be afforded the basic freedom to engage in his/her pursuits without undue invasion of privacy. The duty to honor an expectation of a particular right, such as privacy, is determined not only by the person’s role and responsibility within the institution, but also quite profoundly by the moral or legal basis upon which that right is asserted. For instance, legal scholars have argued that staff members who have been informed of

active surveillance technologies at the time of nursing home employment, simply by virtue of continuing their employment, imply consent to the use of these technologies and its implications for their privacy.⁵ On the other hand, no reasonable person would object to a physician requiring privacy to perform an invasive procedure on a patient. The level of access to digitally captured health information that should be provided to state and federal oversight agencies and payors is more problematic, but may be addressed by developing mechanisms that offer person-specific data with the “minimum necessary” private information as defined by the Health Information Portability and Accountability Act (HIPAA), while offering greater access to de-identified group level data.⁶

CareMedia: Current Status and Conflict Resolution Strategies

The authors recently completed video and audio recordings of fifteen (out of sixteen) consenting residents in the non-private spaces of a community-based dementia unit twenty-four hours a day, seven days a week, for twenty-five days. In addition to collecting baseline demographic data, psychopathology and health rating instruments were completed biweekly by a clinical research associate in conjunction with the nursing home caregivers in order to enable us to compare and validate the findings of our computer-based approach with data obtained by human observers. The ensuing discussion regarding our pragmatic approach to the central ethical concern – privacy and confidentiality protections – and relevant issues of the informed consent process puts forward the positions we have embraced in addressing the ethical challenges which arose during the current round of filming. Admittedly, both the nature of the ethical dilemmas and our proposed solutions thereto will evolve as the technology matures.

What Rights are Impinged Upon by Video and Audio Surveillance?

The ethical motivation behind the CareMedia project is to provide technological tools that will facilitate improved assessments of the quality of patient care in LTC facilities with the goal of improving the QoL of demented, and often debilitated, residents. The central tension encountered in the implementation of our research methodology was to advance the technology development while respecting the privacy and confidentiality interests of all relevant stakeholders. We begin the discussion with a concise overview of the legal aspects of research-related privacy intrusions in LTC, since these facilities are commonly resource-poor and risk-averse. The moral basis of privacy rights, particularly the interest theory of rights, is presented next in order

Table 1

Ethics of Video Surveillance in Nursing Homes: Stakeholders and their Interests

Stakeholder	Interests
Residents	<ul style="list-style-type: none"> • Quality-of-Life (QoL) • Quality-of-Care (QoC) • Privacy • Confidentiality • Freedom from abuse and neglect
Professional Staff (e.g., physicians, nurses)	<ul style="list-style-type: none"> • Reliable, valid data to guide assessment and treatment • Confidentiality of medical records • Privacy with residents • Protection from malpractice or wrongful allegations
Non-professional Staff (e.g., housekeeping)	<ul style="list-style-type: none"> • Privacy • Protection from wrongful allegations
Nursing Home Administration	<ul style="list-style-type: none"> • Maximize QoL and QoC for residents • Minimize legal risks to facility • Optimize fiscal health of facility
Families and Visitors	<ul style="list-style-type: none"> • Privacy • Optimize QoL and QoC for loved one
Oversight Agencies (e.g., state surveyors)	<ul style="list-style-type: none"> • Reliable, valid QoL and QoC data upon which to base (re-)certification • Investigate complaints promptly, aided by surveillance data
Payors (e.g., Medicare, Medicaid)	<ul style="list-style-type: none"> • Documentation of quality measures as is done by the Nursing Home Compare website • Estimation of effort of caring for residents, and thus appropriate payments to nursing facilities • QoL and QoC consistent with state and federal guidelines
Staff Unions	<ul style="list-style-type: none"> • Optimize work conditions • Minimize risk of malpractice or wrongful accusations
Clinical Researchers	<ul style="list-style-type: none"> • Reliable, valid data collection and analysis • Appreciation of care processes • Appreciation of ethical challenges • Appreciation of advantages and limitations of technology in real-world settings • Ability to conduct research with adequate safeguards while accommodating minority dissent

to illustrate a pragmatic approach to resolving ethical dilemmas that arose during the implementation phase of this project.

Privacy: The Legal Perspective

Warren and Brandeis, in their seminal writings on the concept of privacy law, have defined privacy as the “right to be let alone.”⁷ Subsequently, the legal concept of privacy has differentiated to encompass three major categories: physical privacy, informational privacy, and decisional privacy.⁸ The CareMedia project potentially encroaches upon physical and informational privacy by capturing images, voices and activities of nursing home residents and others in shared spaces, but does not appear to impinge upon decisional privacy. The United States Supreme Court has held that the Fourth Amendment (and in some cases, the First, Fifth, Ninth and Fourteenth Amendments) upholds the expectation of privacy in those situations which society would consider *reasonable*.⁹ The question becomes one of explicating the ethical and philosophical underpinnings of reasonableness.

Translating the above argument in terms of the LTC setting, what are reasonable “zones of privacy” within such residential facilities, and to what extent do they apply to the various stakeholders identified in Table 1? In the absence of explicit statutes governing reasonable zones of privacy within LTC institutions, we are compelled to rely upon court opinions offered in other similar settings for guidance. For example, courts have previously ruled the common areas of residential buildings (like hallways) as public, while a greater degree of privacy is accorded within the common areas of hospitals and prisons which are regarded as “semi-private.”¹⁰ The expectation of privacy is also informed to a great extent by the person(s) affected. The Omnibus Budget Reconciliation Act (OBRA) lists amongst its nursing home resident rights, “the right to privacy with regard to accommodations, medical treatment, written and telephonic communications, visits and meetings of family and of resident groups.”¹¹ The procedures of the CareMedia project would clearly impinge upon these rights if the recordings took place in the absence of informed consent from the residents or their legally authorized representatives.

Nursing home employees, in contrast, appear to be entitled to limited expectation of privacy. The Omnibus Crime Control and Safe Streets Act of 1968, also known as the Federal Wiretap Act, permits *silent* video surveillance without the need for consent, and audio recording when at least one party to the conversation has given consent, though certain states require consent of all parties involved.¹² Legal scholars have argued that this Act protects employers from prosecu-

tion when the expressed purpose of the surveillance is supervision or evaluation of the employees.¹³ Moreover, continued employment in the context of prior notification of electronic surveillance technologies within the facility implies informed consent, and thus would further diminish the staff's reasonable expectation of privacy. Still others have asserted the distinction between privacy rights for professional versus nonprofessional staff, lobbying for greater physical and informational privacy for professional staff. None of the above arguments, however, would likely extend to spaces such as staff locker rooms which would be considered private.

right emanates from the interests of those that the right is intended to protect or facilitate. The right to privacy, from this vantage point, is viewed as protecting and advancing the ability of affected parties to retain effective control over a zone of intimacy that encompasses their person and aspects of their private lives and conduct. Having effective control over such a zone of intimacy is essential for individuals' ability to preserve the personally meaningful ways in which they signify and differentiate various grades of personal relationships from different kinds of more formal relationships, and public roles and persona from their private lives.

The interest theory of rights seeks to resolve such conflicts by attending to the underlying interests of individuals that such rights serve to secure, and searching for resolutions that are maximally responsive to each of these underlying interests.

A more problematic issue is the extent to which privacy rights apply to visitors. The courts have been divided in their opinions regarding the privacy rights of "casual, transient visitors," basing their determinations primarily on the nature of the relationship between the nursing home host and the visitor, and the area of the facility within which the privacy right is asserted.¹⁴

Privacy: The Moral Perspective

The very organization of this discussion into a legal and a moral perspective highlights the fundamental conceptual and semantic complexities of capturing all that is subsumed under the rubric of privacy rights. Prominent scholars have dealt with this issue by defining it variously as a value or a moral claim, or as a legal right.¹⁵ From the moral perspective, privacy is viewed as a prerequisite for the pursuit of personhood, freedom and responsibility. This deontological perspective dates back to antiquity when both the Greeks and Romans recognized and acknowledged the public (*res publicae*) and private (*res privatae*) spheres of life. As Allen argues, the emphasis in these ancient cultures was to idealize and celebrate the domain of public, community engagement, while dismissing the private world as mundane; in contrast, modernity places the highest moral value on the private sphere while accommodating public impingements for the sake of collective welfare.¹⁶

Seminal to the ethical deliberations about the CareMedia project are the premises of the recently articulated interest theory of rights.¹⁷ According to this perspective, the normative force for, and justification of a

One advantage of the interest theory of rights is that it recognizes that the rights of individuals can come into conflict. LTC facilities represent a context in which such conflicts frequently exist. For example, simply because residents are demented or debilitated does not mean that they have lost all interest in retaining a sphere of intimacy surrounding their personal and

private life. In fact, because the ability of such persons to retain effective control over this zone of privacy is often compromised by their dementia or other medical conditions, they frequently require the assistance of caregivers in retaining the integrity of this sphere of privacy. At the same time, however, LTC facility staff have obligations to look after the welfare interests of residents, and these obligations frequently require intrusions into their intimate spaces. As a result, LTC facilities already have to balance the provision of a safe and commodious environment, in which the health and welfare interests are supported and advanced, with the need to support residents in retaining as much control as possible over a legitimate zone of intimacy.

The interest theory of rights seeks to resolve such conflicts by attending to the underlying interests of individuals that such rights serve to secure, and searching for resolutions that are maximally responsive to each of these underlying interests. It is our contention that the CareMedia project should be understood within the larger context of conflicting rights that already exists in many LTC environments. Although the CareMedia project creates additional intrusions into the privacy of residents, it is our contention that this intrusion, and the specific ways in which it was both targeted and limited, can be justified by the important ways in which this technology is responsive to the underlying interests that generate the rights in question.

Privacy Protections

Although the technology employed within CareMedia may be viewed as in tension with, or intruding upon the

privacy rights of various stakeholders, we assert that these intrusions are limited, and focused in ways that are fundamentally responsive to the underlying interests of the dementia unit residents, staff, and transient visitors.

The intrusion into the living spaces of dementia residents and their caregivers by the real-time data capture appears to be justified on several grounds. First, the compromised decision-making autonomy of cognitively impaired residents necessitates that caregivers have access to their living spaces in order to assess, monitor and safeguard their physical and emotional health. The statistics cited in the aforementioned GAO report pertaining to LTC resident abuse and neglect problems highlight the importance of technologies that can monitor the well-being of cognitively impaired residents in real-time, permitting accurate reconstruction of events as dictated by clinical need.

Second, although the technologies of CareMedia gather a wide range of information about the spectrum of a nursing home resident's life, they also contain concrete mechanisms for limiting these intrusions in important ways. Efforts to limit privacy intrusions include but are not limited to: (a) excluding private spaces from our recordings, (b) restricting the filming to only certain common areas of the dementia unit so as to provide more privacy for families and visitors, (c) providing ample written information to all relevant stakeholders regarding the study aims, procedures, scheduled period of filming, and contact information for the principal investigators, (d) de-identifying the voices and faces of all participants in any presentation of results outside the immediate research team, (e) developing machine learning algorithms that flag only events of clinical relevance, and (f) implementing several layers of password and firewall protection to prevent data breach by non-authorized individuals.

Finally, we assert that the nursing home staff members' interest in being free from observation while they perform their duties is trumped by their obligation to permit data collection that will improve the QoC and QoL of the very residents they care for, and by the need to continuously evaluate and upgrade their caregiving skills. While CareMedia may be viewed by some nursing home personnel as "big brother" hovering over their lives, it would, in fact, provide "hands on" clinical data for continuous QoC improvement initiatives. Moreover, these video and audio recordings would speak loudly and clearly to wrongful allegations of staff misconduct, potentially providing further acknowledgment and support to demoralized nursing home caregivers.

Confidentiality

CareMedia is subject however to an added layer of ethical complexity since the research is situated at the intersection of individual-centered and public health ethics, simultaneously acquiring data about individuals and groups, and incidentally recording non-participants who must then be de-identified. The objectives of our study are not confined simply to elements of individual well-being, but also to exploration of the dynamic reciprocal interactions of these individuals with aspects of their physical and social environment. Indeed, clinical or psychosocial phenomena in LTC facilities rarely affect only select residents in uniquely specific ways; thus, an investigational approach that examines individuals within a broader ecological context, while attempting to protect the basic interests of all parties involved is necessary. The most dramatic assertion of the *individual-centered* notion of privacy presents itself in our research when a legally authorized representative of a resident not only refuses to offer informed consent, but also feels empowered by "privacy rights" to disallow any video or audio recordings whatsoever in the shared spaces of the dementia unit, even if their loved one can be rendered unidentifiable. How should the refusal of a substantial minority be respected in the context of an overwhelming majority of individuals who *do* consent? To what extent must the collective good that may result from the insights yielded by this study be subservient to the specific privacy interests of each individual who may be captured by our recordings?

For the purposes of this report, we define confidentiality to be synonymous with informational privacy, referring to the duty to protect personally identifiable patient information from disclosure to unauthorized individuals. The Health Insurance Portability and Accountability Act (HIPAA) has enumerated sixteen identifiers that must be removed in order for private health information to be entered into and used as research databases *without* the patient's authorization. The two unique identifiers that are central to the CareMedia research are facial images and voices. Since all residents and staff members are approached for informed consent, the confidentiality issue applies principally to those who do not consent, and those whose information (video/audio clips) may be shared in public forums outside of the immediate research team. An additional area of concern that arises is the fact that technologies do not currently exist to block from recording, *in real-time*, persons who are non-participants. As a result, the de-identification process is deployed only after the filming is completed, and thus a time lag exists between the completion of the study and de-identification of non-participants during which these individuals could in theory be identified by third parties.

Since staff and visitors are also being recorded, HIPAA would appear to have limited relevance in the context of our research. Moreover, our interest lies as much in the capture of “patient” information as it does in “health” information, which is the substance of HIPAA. Neither the legal mandate nor the spirit of HIPAA appears to be well-positioned to encompass affect, behaviors, activity patterns and social interactions which are the gist of CareMedia. If the purpose of confidentiality is to de-identify and protect “sensitive” information, who determines the sensitivity of and access to the information? Under what conditions can the data be compelled to be released? Historically, federal certificates of confidentiality have been available to protect human-subjects research involving potentially stigmatizing or sensitive issues; however, these also apply only to the subjects themselves and do not necessarily protect the research facility, or other participants who are not research subjects *per se*. Without the protection offered by a mechanism such as the federal certificates of confidentiality, it is understandable that research facilities would fear legal consequences, and hence abstain from research activities without which there is little hope of addressing chronic plaguing clinical problems.

Confidentiality Protections

Protection of confidentiality is a formidable challenge since we collect personally identifiable information in the form of facial and body images and voices. We typically offer the option of obscuring faces and voices to non-participants, but in extreme situations, we have the capability to delete individuals from scenes entirely. The latter process is, however, considerably more labor-intensive, costly, and counterproductive to our goal of examining social interactions. Faces and voices of all study participants are de-identified in any presentation of data outside the immediate research team.

Some potential study participants have raised the objection that the de-identification process takes place only *after* the filming is completed, and fear that third parties may gain access to the recordings before non-participants are de-identified. The longer-term goal is to develop technologies that will automatically record (in real-time) only those who are identified by the computers as study participants. In the interim, data are protected by a firewall and the added security of a Virtual Private Network (VPN). Essentially, only those investigators, who have two separate passwords, and a key to the locked data processing lab, would be able to access the information, and the data are not subject to exploitation by internet hackers. Ultimately, we envision contemporaneous data analysis so as to obviate the need to store raw video and audio data;

all that will remain will be the derived metadata. Such an advance will require that a data safety monitoring board is actively involved in verifying that the results of our investigations are not based on fraudulent raw data that are immediately discarded and therefore not available for further scientific inspection.

Informed Consent

Educational Component

Since the video and audio recordings are not limited specifically to study subjects, we were ethically obligated to educate all individuals who may have access to the dementia unit regarding the objectives and procedures of the study. In order to honor “cold calling” policies for research, the nursing home administration initially mailed an introductory letter on their letterhead with a simply worded two-page CareMedia study announcement to the legally authorized representatives of the dementia unit residents for their review. The legal proxies were encouraged to contact either the nursing home administration and/or the research team with any questions or concerns. Within two weeks of this mailing, the families were telephoned by the dementia unit social worker to obtain their permission for the research team to establish contact with them directly. With one exception, all legally authorized representatives agreed to do so. Subsequently, several educational meetings were offered in the evenings to the families of the dementia unit residents. Typically, these meetings were poorly attended; however, families were very receptive to phone contact in compliance with “cold calling” policies. In addition to the general educational meetings for families, specific training sessions were scheduled with all staff members who would have access to the dementia unit during the study period. Upon completion of this educational component, families were notified via letter of the date of study initiation four weeks ahead of time. Moreover, a sign was placed on the entrance of the dementia unit two weeks prior to and throughout the study period informing all who entered of the title, objectives, and procedures of the study as well as the name and contact information for the principal investigator and the clinical research associate. They were specifically informed of the filming in the shared spaces of the dementia unit, and the location of space(s) that were not being filmed in order to provide them more privacy.

Subject Assent

An attempt was made to obtain affirmative agreement for study participation from all residents, noting any verbal or nonverbal communication of dissent as disapproval for study participation. Due to the advanced stages of their neurodegenerative illness, no resident

was able to demonstrate even the most basic understanding or appreciation of the fact that we would be filming on the dementia unit for research purposes, the voluntary nature of their participation, or its implications for their well-being. We took the added precaution of ascertaining from the nursing home caregivers whether the timing of our visit was “just a bad day” for the resident, or whether they truly were very cognitively limited, precluding meaningful assent. Supporting our judgment that these residents lacked capacity for assent or dissent was the fact that a durable power of attorney for health care made treatment decisions in every case. The components of truly valid assent/dissent, and the procedures implemented to obtain it from severely cognitively impaired potential research subjects are important areas for future research.

Informed Consent Process with Legally Authorized Representatives

All legally authorized representatives, with one exception, provided proxy informed consent for their loved one to participate in our research, with the clear understanding that there would be no direct benefits from this research to their loved one (“non-therapeutic research”). It is important to clarify, however, that these individuals were legally authorized to make *clinical* decisions on behalf of their loved ones, not necessarily research enrollment decisions. None of our study subjects had specifically-stated, written documentation of advance research directives. It is therefore unclear to what extent the proxy informed consent represented a substituted judgment on behalf of the study subject. As with the need to determine the components of valid assent/dissent, there is considerable national debate pertaining to the need to examine how legally authorized representatives for research initiatives are identified and appointed, and the nature of their deliberations about enrolling their loved one in a research project.¹⁸

A major ethical obstacle that has previously arisen during the implementation of our research at another site merits deeper reflection: a resident, his/her legal proxy or staff member not only declines study participation but objects to *any recordings* taking place on the unit whatsoever. In contrast to traditional clinical research which typically concerns the rights of study participants only, our study captures many non-participants whose interests must be proactively protected as well. We attempted to do so by posting the aforementioned study notice on the dementia unit entrance two weeks prior to and throughout the study period. Legally authorized representatives of our study subjects were encouraged to inform regular visitors to the dementia unit of the nature and inclusive dates of our study. Additionally, the Commonwealth of Pennsyl-

vania’s Institutional Review Board advised us to keep a large, common activity space un-instrumented as a compromise in order to partially accommodate those who may be opposed to recordings taking place on the unit. The broader ethical tension here is balancing and respecting the refusal of a minority of potential subjects and/or their legally authorized representatives with the overwhelming majority of individuals who choose to participate in the study, and the benefits that may result from our findings for future LTC residents with dementia.

Informed Consent with Staff Members

No staff member objected to the recordings on the unit as long as they had assurance that their faces and voices would be de-identified. The nursing home administration had agreed to accommodate non-consenting staff member(s) on another unit in the facility without compromising care on the study unit. Staff members were also informed that physical or sexual abuse of a resident was the only condition that we were required to report to the nursing home administration. Moreover, the nursing home would not have access to any of the filmings, and there would be no punitive actions against staff members for study participation or refusal. Local agencies which supply nursing staff on an as-needed basis were informed ahead of time by the nursing home administration of our study so as to provide only those individuals with no serious objections to the study procedures.

Future Directions

CareMedia challenges and potentially expands the dialogue pertaining not only to the ethics of surveillance technology research, but also to the widening gulf between individual-centered and public health ethics. We have demonstrated the application of the principles of the interest theory of rights to address the critical issues of privacy and confidentiality protection in an innovative project that films the lives of cognitively impaired nursing home residents and their caregivers continuously in real-time. In addition to the strategies we had to develop to address the principal ethical issues, an immediate lesson for us has been the need for LTC facility administrations to carefully consider and articulate a research mission statement that, like the clinical mission statement, would be reviewed with the resident and his/her legally authorized representative prior to admission to the facility. Ideally, the agreement to abide by this statement should be obtained in writing. While no generic mission statement could possibly hope to cover specific details of potential projects, the residents and/or their legally authorized representatives should have a clear understanding that this facil-

ity participates in clinical research, and that their full consent will be sought if they are appropriate subjects for specific projects. The authors have currently piloted this idea to a prospective LTC facility that plans to participate in CareMedia research. The proposed research mission statement discloses to future residents and families the fact that this facility participates in research that involves filming in the shared spaces of the dementia unit periodically, and that they have no objection to the filming *per se*, provided they have no obligation whatsoever to be study participants. The research mission statement will be part of the resident's admission packet, and will be reviewed verbally with them by the admissions coordinator of the LTC facility.

In addition to a research mission statement, a data safety monitoring board comprised of research investigators, nursing home administration and staff, as well as cognitively intact residents, family members, and an ethicist, could be implemented by the LTC facility to regularly and proactively identify and remedy potential problems that arise during the course of a research project. Such a mechanism may well avert the need to seek redress for grievances from external sources. In order to facilitate such time-consuming participation from facilities that are already resource-poor, research teams must be prepared to reimburse the relevant sites for all of their effort. Alternatively, incentives that are critical to the needs of the long-term care facility (e.g., staff education in behavioral management) have to be identified if the facility is to be expected to express any motivation for participation in the project.

In our view, the current criteria for qualification for a federal certificate of confidentiality are overly narrow and restrictive. Specifically, they protect the privacy of individual subjects under most situations; however, they provide no legal protection for the facility *per se*. Moreover, applications for these certificates are not uncommonly denied on the grounds that adequate reappraisal of the informed consent process would suffice. This logic fails in sensitive research where obtaining informed consent from all potential persons (irrespective of whether they are study participants) may be impracticable or simply impossible. A more inclusive, flexible approach needs to be applied in determining which projects warrant a certificate of confidentiality in order to encourage participation in sensitive research. As an example, one of our research sites that is notably resource-poor withdrew its intent to participate in the study after one of its cognitively impaired residents wandered into an unlocked bathroom and drowned in a whirlpool. Would this not be precisely the type of facility where research would shed the greatest light and inform clinical care processes most acutely?

As this project unfolds in several LTC facilities, we will have further data and experience to report. To date, we have reported on the obstacles and challenges of undertaking such research in resource-poor environments, and the strategies we employed to minimize the ethical conflicts between our desire to validate a promising surveillance technology and our obligations to respect the privacy and autonomy of facility residents, staff and visitors. In future reports, we hope to convey the development and implementation of mechanisms and approaches that are conducive to such research as the technology evolves and matures, and additional challenges we encounter as our study population becomes more ethnically diverse and we move to the data analysis phase of the project.

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References

1. G. Moak and S. Borson, "Mental Health Services in Long-Term Care," *American Journal of Geriatric Psychiatry* 8 (2000): 96-101.
2. U.S. General Accounting Office, *Nursing Homes: Prevalence of Serious Quality Problems Remains Unacceptably High, Despite Some Decline* (Washington, D.C.: U.S. General Accounting Office, 2003): at 2.
3. E. M. Carlson, "Videotaping to Protect Nursing Facility Residents: A Legal Analysis," *Journal of the American Medical Directors' Association* 1 (2001): 41-49.
4. S. N. Cottle, "'Big Brother' and Grandma: An Argument for Video Surveillance in Nursing Homes," *Elder Law Journal* 12 (2004): 119-123.
5. L. E. Rothstein, "Privacy or Dignity?: Electronic Monitoring in the Workplace," *New York Law School Journal of International and Comparative Law* 19 (2000): 379-412.
6. Department of Health and Human Services Office for Civil Rights, "Summary of the HIPAA Privacy Rule," May 2003, at <<http://www.hhs.gov/ocr/hipaa/privacy.html>> (last visited June 20, 2006).
7. S. Warren and L. Brandeis, "The Right to Privacy," *Harvard Law Review* 4 (1890): 193-220.
8. A. L. Allen, "Privacy in Health Care," in *Encyclopedia of Bioethics*, Volume 4, W. T. Reich, ed. (New York: Macmillan 1995): 2064-2073.
9. T. Kohl, "Watching Out for Grandma: Video Cameras in Nursing Homes May Help to Eliminate Abuse," *Fordham Urban Law Journal* 30 (2003): 2083-2107.
10. *Id.*
11. United States Code, 42 U.S.C. [section]1395i-3c, December 2001, available at <<http://www.access.gpo.gov/uscode/uscmain.html>> (last visited June 20 2006).
12. United States Code, 18 U.S.C. 2510-2522.
13. E. Adelman, "Video Surveillance in Nursing Homes," *Albany Law Journal of Science & Technology* 12 (2002): 821-838.
14. Kohl, *supra* note 9.
15. Allen, *supra* note 8, at 2064.
16. Allen, *supra* note 8, at 2067.
17. J. Waldron, "Rights in Conflicts," *Ethics* 99 (1989): 503-519.
18. Y. H. Kim, P. S. Appelbaum, D. V. Jeste, et al., "Proxy and Surrogate Consent in Geriatric Neuropsychiatric Research: Update and Recommendations," *American Journal of Psychiatry* 161 (2004): 797-806.