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"Nobody Tells You Anything": Ethics of Privacy in Assisted Living

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“Nobody Tells You Anything”: Ethics of Privacy in Assisted Living

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Emma Cooke, B.A., Smith College, 2014

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An abstract of
A thesis submitted to the Faculty of the James T. Laney School of Graduate Studies of Emory
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Abstract

“Nobody Tells You Anything”: Ethics of Privacy in Assisted Living

By Emma Cooke

Assisted living (AL) was developed as a “homelike” alternative to nursing care for older adults; however, as the AL population has aged, its role as a home and community is balanced with its role as a healthcare delivery site. Enforcement of the Health Information Privacy and Accountability Act (HIPAA) illustrates this dichotomy. AL, as a patient care site, must abide by regulations restricting health information sharing among residents and staff; however, in the setting of a community with longstanding peer relationships, many residents find these regulations frustrating.

HIPAA was established to protect patient privacy, but is rooted in a Western conception of autonomy that may not fully recognize individual embeddedness in a larger community. Alternative conceptions of autonomy such as relational autonomy and ethics of care contextualize decision-making within the context of a community network, and point towards ways to reconcile the two equally important values of personal privacy and social connectedness.

This study analyzed qualitative data collected over a two-year period at Parkside, an AL community in Atlanta, to address the question: *what are the health information sharing practices in AL that help or hinder residents’ maintenance of self?,* with *maintenance of self* defined as the process of continuously upholding and refining a sense of individual identity and meaning throughout life. We identified four health information sharing practices: conversing about health, obtaining health information through observations in the environment, using health information, and maintaining privacy. We then identified four overarching themes within these practices: (1) Providing information about shared life stage and health circumstances builds community; (2) Avoiding health information disclosure or providing incomplete information leads to frustration and further questions; (3) Inserting medical information into public space medicalizes the social environment; and (4) Negotiating privacy boundaries in health information requires compromise between residents and staff.

These themes illustrate HIPAA’s limitations in the AL setting; accordingly, we recommend developing a health information advance directive, allowing residents to designate the amount of health information they would like to share in the event of hospitalization. This policy would allow for resident choice and better recognize the unique needs of AL residents.

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Table of Contents

Chapter 1: Privacy, Social Relationships, and HIPAA in Assisted Living

Assisted living (AL) is a familiar part of the American landscape. From small "board-and-care" style homes to larger apartment-style dwellings, in 2016 these communities provided housing and assistance with daily activities to an estimated 811,500 people in the United States (Harris-Kojetin et al., 2019). At the same time, there were an estimated 1,347,600 American residents of nursing homes (NHs) (Harris-Kojetin et al., 2019). By contrast, prior to 1980, AL was functionally nonexistent: older adults requiring some assistance with activities of daily living (ADLs) like eating, bathing, and toileting, lived either in NHs or in the community (Wilson, 2007). The creation and popularization of AL in the United States has taken place in the past forty years, originally rooted in a desire to provide a less-regulated option for the growing number of older adults and their families seeking long-term care.

Assisted living was originally developed as a more "homelike" alternative to traditional nursing care, one that would "foster resident privacy and autonomy" (Street, Burge, Quadagno, & Barrett, 2007, p. 129). One longtime NH resident's ideal home typifies the original vision of what assisted living would offer: "She could have privacy whenever she wanted, and no one could make her get dressed, take her medicine, or go to activities she did not like. She would be Jessie again, a person living in an apartment instead of a patient in a bed" (Wilson, 2007, p. 9). Unlike in NHs, AL residents would be given the opportunity to make choices about their care and their daily lives, while still being provided with the support necessary to function (Wilson, 2007).

This ideal was soon met with challenges. ALs sought to enable aging in place, meaning that residents would not be required to relocate if and when their needs became more substantial (Chapin & Dobbs-Kepper, 2001). However, due to differing legislative attitudes, some states (e.g., Virginia) imposed criteria limiting the services that could be provided, requiring residents with higher degrees of disability to arrange for outside providers to meet those needs not covered by the facility itself (Wilson, 2007). Additionally, early ALs generally operated under a private-pay model, which, while allowing for more flexibility in services offered, also limited the number of people who could access AL at all (Wilson, 2007). Over time, some states, such as Oregon, began to allow the use of Medicaid waivers for AL care, rooted in the recognition that many state residents were in NHs and wished to move out, while others had care needs well suited to the AL setting, but lacked the ability to pay for it (Wilson, 2007). Nonetheless, to this day, the majority of AL residents pay for their care out of pocket, compared to a small fraction utilizing Medicaid (Harris-Kojetin et al., 2019).

Despite these financial and regulatory challenges, AL has continued to grow in popularity. Small companies providing AL services in the 1980s and 1990s grew in size and became publicly traded corporations, leading to a shift in marketing strategy in order to reach as many potential customers as possible (Harris-Kojetin et al., 2019). At the same time, the AL population has shifted to include increasingly disabled residents: more than half of all AL residents are over 85, one third require assistance with three or more ADLs; half have two or three chronic conditions, while 26 percent have between four and 10 (Harris-Kojetin et al., 2019; Khatutsky & Kojetin, 2016). Many of these residents hope to age in place; this wish is particularly important given that relocation in older adults can lead to social isolation, loss of routine and personal possessions, and other negative effects (Chapin & Dobbs-Kepper, 2001).

As the AL population has become older and sicker, AL administrators and state regulatory agencies have been required to develop policies for managing this aging population. These policies, intended to provide guidance regarding which residents are eligible for AL care, differ between states and between individual ALs. One study of 139 ALs in Kansas identified the wide range of AL admission policies: while 77 percent of AL administrators would accept a new resident who used a wheelchair, only three percent would accept one who required 24-hour nursing care (Chapin & Dobbs-Kepper, 2001). While ALs in Kansas were shown to be more stringent in their requirements for residents, Kansas is not dissimilar from other states in that ALs are free to develop their own policies about admission and retention. Accordingly, it is worth noting that *any* AL's willingness to accept a resident who requires constant nursing care—even if such ALs are in a small minority—suggests some shift in the conception of AL's role. Furthermore, ALs are generally more willing to retain residents whose care needs increase after they are residents than they are to admit new residents who have these needs on arrival (Chapin & Dobbs-Kepper, 2001). In addition to the variation between individual ALs, states also have different criteria for acceptable AL residents: Virginia stringently regulates eligibility for AL, while Oregon is relatively permissive to sicker residents who otherwise might not gain access to AL (Wilson, 2007).

With significant differences between the populations of different ALs—some willing to take much more disabled residents than others—the definition of an AL, and the role it should adopt in its residents' medical care, has become less clear. Given the increasing needs of the resident population, many ALs now have nurses on their staff, a contrast from the traditional AL model in which most care is provided by unlicensed workers (M. M. Ball, Kemp, Hollingsworth, & Perkins, 2014).

AL in Georgia: Assisted Living Communities and Personal Care Homes

Additionally, many states (including Georgia, where the data for this study were gathered) have established a legal distinction between personal care homes, which provide relatively little assistance to residents, and Assisted Living Communities (ALCs), which provide for a wider range of medical needs (though the specific terminology used for these two categories varies from state to state) (NationalCenterforAssistedLiving, 2017). In Georgia, a personal care home (PCH) is legally defined as "[a]ny dwelling, whether operated for profit or not, which undertakes through its ownership or management to provide or arrange for the provision of housing, food service, and one or more personal services for two or more adults who are not related to the owner or administrator by blood or marriage" (NationalCenterforAssistedLiving, 2017). By contrast, an ALC is defined as "[a] personal care home serving 25 residents or more that is licensed by the department to provide assisted living care. Assisted living care means specialized care and services including personal services, the administration of medications by a certified medication aide, and the provision of assisted self-preservation" (NationalCenterforAssistedLiving, 2017). In summary, ALCs must meet comparatively more challenging regulatory standards as compared to PCHs. In Georgia, ALCs must meet space requirements (e.g. minimum square footage, minimum number of bathrooms), provide certain kinds of medical services (e.g., counseling on flu vaccination), and retain a larger number of trained staff (NationalCenterforAssistedLiving, 2017). This higher level of regulation regarding care workers, physical plant specifications, and necessary health services indicates a shift in AL to a more medicalized model.

Yet despite these changes, it is important to note that ALs, even those with nurses on staff, do not offer 24-hour skilled care, and most care (such as assistance with ADLs and medication administration) is provided by "proxy caregivers" who may not have any specific healthcare training (NationalCenterforAssistedLiving, 2017). This lack of professionally trained staff, while it serves to differentiate AL from traditional nursing facilities, is at odds with the increasingly frail AL population. As a result, positive conceptions of AL in the late 20th century have been to some extent replaced with suspicion, particularly in the wake of reports about AL residents whose communities failed to meet their needs (Wilson, 2007). ALs have responded to these concerns with an increased emphasis on establishing and meeting regulatory standards (Wilson, 2007). Nonetheless, unanswered questions remain about how to define AL: who is the target demographic, and to what extent can and should ALs retain residents who are "too sick" for this demographic? AL administrators are also increasingly required to consider the level of medicalization that they feel is appropriate to meet this population's growing healthcare needs.

A More Medicalized Assisted Living

AL has gradually shifted from its original homelike model to one that offers much broader services to a much sicker resident population, enabling residents to age (and often die) in place. Consequently, AL has often been characterized as "the new nursing home" (Roth & Eckert, 2011). The day-to-day experience of an AL resident today may thus be strikingly different from that of a resident in past years. ALs may offer skilled care and/or memory care units, which are subject to additional regulations within the category of AL, but are not held to the same regulatory standards as nursing homes—for example, they are not required to offer 24-hour nursing care (NationalCenterforAssistedLiving, 2017). These AL units allow residents with higher medical need to remain in the community (as can the growing number of continuing-care communities with distinct areas for differing levels of care), but can also lead to stigmatization of these higher-need residents as a result of their greater perceived proximity to death and decline (Zimmerman et al., 2016). At the same time, sicker residents also have the opportunity to remain in their original AL apartments, supported by a variety of assistive technologies (e.g., slings to help transfer residents from beds to chairs) that are more traditionally associated with NHs (Zimmerman et al., 2016). Even comparatively healthy AL residents may find that medical needs, and accommodations for these needs, permeate the AL environment. For example, dining rooms—a social space—may double as sites for medication distribution or finger pricks; even in cases when policy forbids medical care from taking place at dining tables to better facilitate a social, non-medical environment, AL staff may simply situate themselves at the dining room entrance instead (Roth & Eckert, 2011). Thus, as AL has grown to accommodate a sicker resident population, the medical needs of its residents have come to assume a larger role in the resident environment.

Medical needs may also manifest themselves in more subtle ways. One study of a North Carolina AL showed that more impaired residents were more likely to be found in public areas during the day, but less likely to be awake—and, if awake, more likely to be displaying agitation or negative affect (Zimmerman et al., 2007). It is thus likely that AL residents will come into contact with relatively disabled peers in the course of their daily activities, assuming that most residents will enter common areas throughout the day. In addition to agitation and negative affect, sicker residents may also be incontinent (leading to smells of urine in AL corridors) or may fall asleep in public areas (Roth & Eckert, 2011). When these medical needs are in evidence, they may lead to stigma from healthier peers, as in the case of residents sleeping in chairs in the AL lobby: residents and staff, taking note of this practice, complained that the impression it gave was “not the best image” of the community (Roth & Eckert, 2011, p. 5). Indeed, stigmatization of more impaired residents is a known phenomenon, particularly in larger ALs, and particularly against residents with cognitive impairment (M. M. Perkins, Ball, Whittington, & Hollingsworth, 2012). Such stigma has been theorized as a way for residents to differentiate themselves from sicker peers, reflecting anxiety about illness and decline and negative societal attitudes toward aging (M. M. Perkins et al., 2012).

Yet even as sicker residents may be stigmatized by peers or staff, residents who are sick and declining may also elicit sympathy and kindness from other AL community members. In ALs of different sizes and income levels, residents help peers with tasks like pushing wheelchairs and reminding about meals, which can provide a sense of meaning and purpose, while also perhaps distinguishing the helpers from those in need of help (M. M. Perkins et al., 2012). Helping peers and even co-existing closely within shared physical space can also create a sense of intimacy with others and reinforce self-identity in relation to others (Vandenberg et al., 2018).

As sicker residents become more frequent in AL, residents increasingly must negotiate the challenges of "living within an environment that is both someone's home as well as a place of business whose job it is to keep people safe" (Roth & Eckert, 2011, p. 14). As residents with cognitive decline, multiple medical comorbidities, and at the end of life increasingly are choosing to die "in place" (i.e. in AL), their presence in AL requires those around them to face the realities of death and decline up close. These realities may include, as described, living alongside peers who are visibly declining, or experiencing medical intrusions into daily life. They may also include more imminent reminders of death, such as contact with residents who are visibly at the end of life and may be (for example) confined to their beds with the room door open (Ball et al., 2014). Given the prevalence and the visibility of declining and dying residents in AL, as well as the unavoidably communal nature of life in an ALC, death in this setting can be considered a "social event" (Ball et al., 2014). Accordingly, all residents must (and do) engage with death and dying to some extent, as events that will eventually affect them and that already are affecting those in their community. However, legal regulations—specifically, the Health Insurance Portability and Accountability Act (Department of Health and Human Services, 2013; *Standards for Privacy of Individually Identifiable Health Information; Final Rule*, 2002; "What Is Protected Health Information?,"), which restricts health information sharing—affect this engagement in a variety of ways.

The Health Insurance Portability and Accountability Act (HIPAA) and Medical Privacy in Assisted Living

HIPAA was passed in 1996 and modified to its current form in 2013 (Department of Health and Human Services, 2013). Included within HIPAA is the Privacy Rule, which is designed to prevent protected health information, or PHI, from becoming publicly available. The Privacy Rule prohibits covered entities (i.e. those covered by HIPAA, including hospitals, clinics, insurance providers, and government programs such as Medicare and Medicaid) and their employees from sharing patient health information. The 2013 update broadened this scope to include business associates of covered entities as well, a category that includes contractors performing billing, claims processing, and other non-healthcare-related services, who nonetheless have access to PHI (Department of Health and Human Services, 2013). Any entity that provides health care and submits claims for payment to insurers is considered to be a covered entity under HIPAA (Department of Health and Human Services, 2019). As some ALs do provide some health care for their residents, and may also submit insurance claims (e.g. for residents whose costs are covered by Medicaid), they are often considered to be covered entities, and therefore subject to HIPAA (Finnegan, 2013), though the correct application of this designation is not always clear, as will be discussed further later in this chapter.

What happens when HIPAA is applied in an AL setting? Unlike patients in hospitals or clinics, AL residents have ongoing relationships with one another, and absences may be noted and seen as a cause for concern. However, because a hospitalization is classified as PHI, staff members can confirm to residents that a peer has been hospitalized if they are asked about it, but cannot provide any details or updates on their condition. This lack of information can be a source of frustration to AL residents, as one resident observed (Zimmerman et al., p. 542): “[O]f course we’re not allowed to know anything. On the other hand we say we're all one happy family, we're all supposed to be family you know. But they don't tell us that—evidently that's a government regulation." For this resident, AL staff withholding information about resident health belies the community's stated aim of being a "happy family," or a homelike environment. Another resident expressed similar displeasure with the absence of information about peers: "[A]nd HIPAA, I mean you just fall into the black hole of Calcutta, which I think is not right…I don't know why they overplay that [HIPAA]. And I think that does something about this feeling of closeness, so it becomes more of an indifference attitude" (Zimmerman et al., 2016, p. 539). Like the first resident, this person's concerns about HIPAA reflect the sense that a lack of information impairs social dynamics between residents. In their view, residents may choose not to (or be unable to) form close connections with one another, due to the recognition that these friends and acquaintances will eventually vanish with little or no explanation. The authors of this study thus note a tension between HIPAA's intended effect and its unintended social consequences: "[T]he enforcement of HIPAA to not discuss residents' death or hospitalization created social distance among residents (a bad outcome), at the same time it promoted privacy (a good outcome)" (Zimmerman et al., 2016, p. 544).

Residents are not the only individuals in AL grappling with the effects of privacy regulations. Administrators and staff are also affected. One AL director, asked about how resident deaths were discussed at their community, responded, "Unfortunately because of HIPAA, I can't give out a lot of information to the residents and that frustrates the residents to no end because I can't tell them how their neighbors are doing" (Ball et al., 2014, p. 8). Another staff member in a different study seconded this description, stating that residents' inability to receive updates on peer health was "like you sitting with somebody all your life or for the last five years of your life and then they're gone [and] you can't explain what happened…they think it's ridiculous and they get very upset" (Kemp, Ball, Hollingsworth, & Perkins, 2012). As a result, residents find alternative strategies to learn about how their peers are faring, including discussion among peers:

> You find that it gets over the grapevine sometimes, because the staff's not really supposed to talk about—that's another one of the rules. They're not supposed to come up here and tell them something has happened. Like if somebody dies and you've got a suspicion that something's happened, you ask them, they'll say, "I can't talk about it." …Well usually it gets out some kind of way because somebody can go snoop and they'll find out and then they'll tell it (Ball et al., 2014, p. 8).

In the same study, residents also described learning of deaths through reading obituaries (or discussing obituaries with those who did), or through seeing fire trucks, grieving relatives, or even bodies being removed from the ALC. The authors concluded that "[s]taff rarely provided, and frequently concealed, death information, despite residents' expressed preferences to know" about peer deaths (Ball et al., 2014, p. 12).

AL residents, who are witnessing the decline and death of peers with whom they may have close relationships, are thus often unable to learn key details of these peers' conditions due to concerns about HIPAA. It is therefore relevant to ask whether this policy—which, though presumably created out of a desire to keep PHI secure, evidently does have at least some negative effects on resident relationships—is even rooted in an accurate interpretation of HIPAA.

Despite the seemingly straightforward designation of a covered entity as a healthcare organization that provides medical care and submits insurance claims, not all ALs are categorized as covered entities. ALs that submit insurance claims electronically are considered covered entities regardless of the frequency of these claims; however, smaller or independent ALs may not submit claims electronically, and thus may not be considered covered entities (Finnegan, 2013). Parkside, the ALC described in this study, is affiliated with a large AL corporation that describes HIPAA on its website and provides a list of communities that are designated as covered entities. However, Parkside itself is not on this list, indicating that its parent company does not consider it to be a covered entity. An AL administrator providing comment on this matter noted that this is a surprising finding, since Parkside engages in practices that would qualify it as a covered entity, including maintaining electronic health records for residents, taking vital signs, administering medications, billing long-term insurers, and contracting with outside healthcare providers (Doyle, 2019). Detailed legal discussion of how and why different ALs do or do not qualify as covered entities is beyond the scope of this research; however, it is certainly worth noting that Parkside's (or, indeed, any AL's) status as a covered entity does not appear to be clear even to those operating the facility itself. Yet despite this legal confusion, many ALs adhere to HIPAA regulations regarding disclosure of illness and death, leading to frustration among residents, as described above.

Implications of HIPAA on social relationships in AL

AL residents' dissatisfaction with information sharing practices is seemingly rooted, at least in part, in residents' concern for the well-being of their peers. A closer examination of the nature of relationships in late life sheds further light on how AL residents' relationships are both important and unique to this life stage. Socioemotional selectivity theory states that older adults tend to prioritize close and/or long-term relationships over more recent or casual ones, and that this preference reflects older adults' sense of limited time in life, and their wish to maximize their emotional satisfaction during this time (Carstensen, Isaacowitz, & Charles, 1999). One study conducted in AL supports this finding and shows that many residents are not interested in developing new relationships with residents (M. M. Perkins, Ball, Kemp, & Hollingsworth, 2013). One resident in this study stated that they avoided close relationships with peers in AL to avoid social obligations from "needy" people, while another noted that "[d]eath and pain are hard to accept" and said that they avoided close relationships for this reason. Residents' seeming preference for longer-term relationships over newer AL-based ones may thus be rooted not only in prioritization of deep emotional satisfaction, but in avoidance of emotionally taxing or demanding situations, such as needy peers or the death and decline of friends—a choice that serves both to protect and to isolate.

Although peer relationships in AL sometimes may appear to be comparatively unimportant, even peripheral, some evidence shows that these "weak ties" are important for overall well-being, and fill a necessary space in residents' lives (M. M. Perkins et al., 2013; M. M. Perkins, Ball, M.M., Kemp, C.L., & Hollingsworth, C, 2013). Other research shows that residents who were socially connected with both residents and staff in their AL were more likely to report life satisfaction, stable or improved quality of life, and a sense of being at home in AL, as compared to residents with fewer social connections (Street et al., 2007). Relationships within the AL may also be the only social contact available to residents: after moving to long-term care, social contact with family and community-dwelling friends can decrease by up to one-half (Port et al., 2001), while another study of AL found that one-third of residents receive no visits from friends outside the AL (M.M. Ball et al., 2000). When maintained, ongoing social contact provides health benefits as well as quality of life benefits, including slowed functional decline, reduced agitation and depression, and decreased mortality in older adults (Zimmerman et al., 2007). It is worth noting that these social relationships, while important, are not necessarily close: residents may form peripheral friendships that do not require an intimate connection (M. M. Perkins et al., 2013). These peripheral friendships may involve simply greeting one another or making light conversation in communal space (Vandenberg et al., 2018), activities that do not entail the same level of emotional engagement as close friendships, but which nonetheless (in the context of ongoing relationships) improved quality of life for AL residents (M. M. Perkins et al., 2013). Thus, even if some residents, by their own assessment, see peer relationships in AL as relatively insignificant, these relationships are still critical for residents to maintain well-being and life satisfaction in AL.

One mechanism by which peer relationships may improve quality of life is through "neighboring" behavior. Peripheral friendships overlap with neighboring behavior, which is described as actions between AL residents that are friendly, helpful, and supportive, but not necessarily indicative of deep ties (Kemp et al., 2012; Pillemer, 2000). Neighboring behavior, which can include expressing concern, helping peers, or exchanging pleasantries, is facilitated by residents being, in one's own words, "all somewhat incapacitated in some kind of way" (Kemp et al., 2012, p. 495). Neighboring also serves as an important and common source of social support in AL, and reinforces ties between residents based on their shared circumstances at end of life. Significantly, the authors of the above study specifically described HIPAA as an impediment to neighboring behavior and thus to relationships in AL, since residents are not able to stay updated on the well-being of their peers (Kemp et al., 2012).

ALs in the United States contain a tension between resident relationships (which improve quality of life, but also promote information sharing and, thus, a potential reduction in privacy) and information-sharing regulations (which, conversely, ensure resident privacy but may hamper relationships). This study aims to examine the question: *what are the health information sharing practices in AL that help or hinder residents' maintenance of self?,* with *maintenance of self* defined as the process of continuously upholding and refining a sense of individual identity and meaning throughout life. As such, this study will assess how health information is shared in the AL setting through the lens of one ALC in the Atlanta, Georgia, metropolitan region and its residents, family members, and staff. Additionally, it will examine the question of whether the competing demands of privacy (as well as the governmental and institutional forces that mandate it) and social connection can be resolved in a way that facilitates maintenance of self; and if so, how. This latter question—specifically, the ethical ramifications of social life in AL—will be discussed in the next chapter.

Chapter 2: Ethical Ramifications of Sharing Health Information in AL

AL is both a home for its residents and, increasingly, a site of medical care. AL residents form relationships with one another, and benefit from these relationships as a source of support (Kemp et al., 2012). However, the increasing medicalization of AL can come into conflict with relationships within the community when residents become ill or are hospitalized. Inability to receive health information about peers in this setting can be frustrating and potentially even harmful to ongoing relationships within the AL community.

How should this situation be evaluated from an ethical standpoint? On one hand, as was discussed in the previous chapter, there is ample evidence for the benefits of social relationships in AL. These relationships are even more critical given that, for many residents, peers in AL come to replace the resident's former social circle in the community (Bennett et al., 2017). Consequently, anything that is potentially damaging to these relationships may be considered—at least to some extent—a threat to resident well-being. At the same time, resident privacy—i.e., what HIPAA is intended to protect—is also clearly a value worthy of consideration. Some studies have described the harmful effects of privacy loss in long-term care settings (Hawes, Phillips, Rose, Holan, & Sherman, 2003; Roth & Eckert, 2011) and while such studies mostly address privacy as it relates to intrusions into personal space and property, some residents indicate their dissatisfaction when medical information is made public as well. (One ethnographic study provides an illustration of this dissatisfaction when a resident, frustrated by waiting for a bathroom, inadvertently disclosed that he needed to provide a urine sample, angrily exclaiming that he had been made to share his private medical information with other residents (Roth & Eckert, 2011).) It is thus important to balance the value of privacy with that of social relationships.

In this chapter, I will aim to identify the tensions between these two important values, and to suggest ways toward resolving these tensions. First, I will consider the ethical principle(s) encompassed by a value for privacy. I will argue that the benefits of privacy lie in both the provider's duty to non-maleficence, the patient's (or, in this case, the resident's) right to autonomy, and the provider and facility's duty to beneficence. Then, I will examine the extent to which HIPAA helps (or does not help) uphold these principles, informed by the frameworks of relational autonomy and ethics of care. Finally, I will consider any disparities between the presumed intent of HIPAA and the way that it experienced and enacted in practice, allowing us to assess and compare the ethical benefits and limitations of HIPAA.

A Principlist Approach to HIPAA's Privacy Rule: What Is the Intent?

Bioethicists Tom Beauchamp and James Childress have described a principlist approach to bioethics, in which questions can be framed using the four principles: beneficence (doing good), non-maleficence (avoiding causing harm), autonomy (facilitating the patient's free choice), and justice (appropriate and fair resource allocation) (Beauchamp & Childress, 2012). Principlism allows for a consistent approach to challenging questions, as different options can be evaluated from the standpoint of each principle in turn to determine their ethical strengths and weaknesses. We can thus ask the question: according to a principlist approach, why is it important to ensure patient privacy?

It is perhaps important to note here that "privacy" in the context of HIPAA refers to "individuals' medical records and other personal health information," and the law "sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization"; however, the term *privacy* is never actually defined in the Privacy Rule itself, nor is there explicit discussion of why it is so critical (Department of Health and Human Services, 2013). Furthermore, despite the Privacy Rule's name, it is intended to preserve *confidentiality*, i.e., the secrecy of specific piece(s) of information. *Confidentiality* is a binary: information is kept confidential, or it is not. *Privacy,* by contrast, is a more general term that refers to a person's ability to limit or control what others know about them. Unlike confidentiality, privacy is a spectrum and operates along multiple axes: a person may have more privacy or less; they may value privacy in some dimensions of their lives but not in others. When information is confidential, it is private; however, a person's medical records being confidential does not mean that they necessarily have privacy in other aspects of their life. Although the phrasing of the Privacy Rule frequently uses the word *privacy* when it is referring specifically to the confidentiality of medical records, it does allude briefly to this distinction: "the Privacy Rule creates, for the first time, a floor of national protections for the privacy of [the] most sensitive information—health information" (*Standards for Privacy of Individually Identifiable Health Information; Final Rule*, 2002, p. 53182). The use of the term *floor* indicates, or at least suggests, a recognition that confidentiality of medical information alone does not mean that privacy is being maintained in other areas. However, as a legal document, the Privacy Rule is concerned primarily with the more mechanical question of how to maintain *confidentiality* (even if the actual term used is still *privacy*). It does not address distinctions in how health information is shared (e.g. with family/friends vs. with strangers; in writing vs. orally; as a decision-making aid vs. as a blackmail tool); furthermore, it does not examine the positive and negative ramifications of sharing this information, or how these ramifications depend on the manner and purpose of the sharing. Without an examination of any of these distinctions, and indeed without a formal definition of privacy written into the law itself, we must determine for ourselves: from an ethical standpoint, what benefits do healthcare organizations provide by enforcing HIPAA? This question does not seek to imply that privacy is unimportant or of questionable value, but rather invites analysis about where the value of privacy does and does not lie.

HIPAA, in its original conception, was intended to facilitate safe transfer of medical records from one healthcare setting to another, and in doing so, prevent harms that might have resulted from people's private medical information becoming widely available (Department of Health and Human Services, 2013). Some possible harms might include termination of employment (for example, if an employer discovered that their employee had a chronic or serious illness) or social costs that might result from a stigmatized condition such as HIV or mental illness. HIPAA reduces—or, in an ideal world, eliminates—the possibility that this information will be made public by the healthcare system against the patient's wishes, and thereby prevents the harm that this information could potentially cause. As such, we may reasonably say that enforcing HIPAA supports nonmaleficence – refraining from causing harm – at least in cases like those above.

One might point out that not all medical information is equal in its potential to harm. Some medical information is not particularly sensitive in nature: knowing that a person had a cold last year, for example, will probably not enable someone else to do them much harm. Of course, one might respond that it would be impossible to make a rule accurately delineating sensitive versus non-sensitive health information; for this reason, the definition of "protected health information" (Hawes et al., 2003) is necessarily broad ("all individually identifiable health information, including demographic data, medical histories, test results, insurance information, and other information used to identify a patient or provide healthcare services or healthcare coverage" ("What Is Protected Health Information?," 2018).) As such, even seemingly non-sensitive health information falls under the rubric of PHI.

Yet non-maleficence is not the only ethical reason for HIPAA's existence. Consider the case of an elderly man deciding whether or not to pursue a risky surgery. If information about his health and this upcoming choice were shared with his family against his will, they might try to influence his decision. Would doing so—intentionally or unintentionally—limit his autonomy? Traditionally, autonomy has been conceived as the "idea that an adult person is a bounded individual who is able to live her life freely in accordance with her self-chosen plan, and ideally *independently* [emphasis original] from controlling influences" (Dove et al., 2017). This conception of autonomy, rooted in the Enlightenment and still present in Western ethical thought (M. M. Perkins et al., 2012), asserts that, to be autonomous, individuals must be able to make their own decisions, manage their personal needs, and function with minimal help from others (or, at least, be able to choose for themselves how much help they prefer to receive). By extension, in this view, autonomous individuals should be primary decision-makers in their own medical care; sharing health information with others would be comparatively unnecessary, since they would participate in decision-making only in a very limited capacity. In a conception of the world where individuals are "islands unto themselves," the involvement of others in the intimate details of one's life may seem unnecessary for individual self-determination, and maybe even intrusive. HIPAA, which was developed within the same Western milieu as this concept of autonomy, may thus be considered an outgrowth of the same ideal. By this argument, if individuals are to be autonomous, they have the right not to involve any third parties, even if this involvement is limited to information sharing alone.

At this point, we have argued that HIPAA may be supported partially by the duty of non-maleficence, by making it harder for sensitive information to fall into the wrong hands, and also is supported by the duty of autonomy (in a traditional conception of autonomy) by ensuring that the patient controls if and how their information is shared. We also might argue, more broadly, that HIPAA is intended not only to ensure that patients avoid *negative* experiences (e.g. having personal information disseminated against their will), but also to increase the likelihood that patients have a *positive* experience. Specifically, patients who know that their healthcare providers will not share information that they provide may feel reassured and/or cared for, because they know that their privacy needs are valued. In turn, these patients would (at least, ideally) gain a more positive relationship with their care team and a better overall patient experience. In other words: restricting health information can also support the duty of beneficence, which, in the context of Beauchamp and Childress' four principles, has been defined as "acting with the best interest of the other in mind" (Aldcroft, 2012); healthcare providers upholding HIPAA are (ideally) acting for the patient's benefit[1], both in the short term (by allowing the patient to share or restrict information and to make decisions in a way that they find preferable) and in the long term (by ensuring that potentially sensitive information remains private).

We have now argued that HIPAA is intended to fulfill three different ethical duties, according to Beauchamp and Childress's principlist framework: non-maleficence, autonomy, and beneficence. However, some people have questioned the interpretation and application of these principles to privacy regulations: does autonomy, for example, truly require making decisions without input from others? Is beneficence truly beneficence if the patient interprets the provider's intentions as anything less than good? We will turn next to these critiques, and to the alternative interpretations of privacy regulations that they invite.

Relational Autonomy: A Challenge to Traditional Conceptions of Autonomy

We have argued that HIPAA fulfills the ethical duty of autonomy by ensuring that patients can control the extent to which (if at all) they involve others in their medical decision-making and

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[1] Of course, one might retort that HIPAA is not only intended for the patient's benefit; it is also intended to prevent legal harms such as patient lawsuits against clinicians or insurers. However, providing for the patient's benefit is clearly at least part of the stated intent; furthermore, although lawsuits are a valid concern, it is likely that most people would consider the goal of patient welfare of greater ethical import.

information sharing. However, this traditional conception of autonomy has been called into question for its focus on the individual, which fails to take into account the context in which the individual is embedded (M. M. Perkins et al., 2012). As a result, traditional autonomy does not accurately describe the experiences or attitudes of people in more collectivistic, non-Western cultures, which traditionally define individuals through their relations to other groups and to society at large (Beauchamp & Childress, 2012). Most pertinently for this study, traditional autonomy also fails to capture the experience of people who cannot live independently, a group that may include people with physical disabilities, mental disabilities, and the very young and old. These individuals, by definition, cannot live in a traditionally autonomous state, in which their lives and decisions are dictated only by their own will. In fact, as will be discussed later in this chapter, some authors have questioned whether even independent people's lives and decisions could truly be considered "autonomous" (Dove et al., 2017; Kittay, 1999). How, then, should we define autonomy in a way that more accurately reflects the lived experience of those dependent on others; for example, the experience of older adults in AL?

A relational definition of autonomy provides an alternative way to conceptualize information sharing and decision making. Broadly, "relational ethics insists that persons be treated as the social, interdependent beings that they are" (Kenny, Sherwin, & Baylis, 2010), and relational autonomy specifically conceives of autonomy as choice within the context of, and informed by, a person's social and cultural context, relationships, and (dis)ability (Dove et al., 2017; M. M. Perkins et al., 2012; Sherwin & Winsby, 2011). A relational perspective of autonomy further argues that internalized attitudes, as well as external factors, may influence choice: older adults, for example, are exposed to widespread cultural biases demeaning them as less competent than other age groups, and potentially influencing their own self-image and willingness to question systemic norms (Sherwin & Winsby, 2011). Consequently, some research gerontologists have argued that relational autonomy requires maintaining an internal conception of the self, such that older adults in AL can maintain and assert their own identity, and use this identity to aid in the decision-making process (M. M. Perkins et al., 2012). Maintaining and refining this individual identity has been termed *maintenance of self*—a term indicating a person's ongoing process of re-assessing and re-affirming their identity through situational and maturational changes throughout their life. Perkins's (2012) model of relational autonomy in AL proposes that maintenance of self occurs within the context of four intersecting forms of capital or human conditions: material (e.g., financial resources), human (e.g., knowledge, education, and other individual attributes), social (e.g., relationships and social status), and psychological (e.g., coping mechanisms and skills), all of which can be brought to bear in coping with the vicissitudes of daily life and the challenges of medical decision-making. Individuals who have successfully maintained self in AL exercise autonomy by continuing to make decisions that strengthen and affirm their identity and self-concept. Significantly, however, relational autonomy does not require that AL residents (or any other group) make decisions without help from others or without being influenced by their environment; rather, these contextual factors represent part of the resident's self, and thus part of the decision-making paradigm.

In recent years, there have been greater calls for relational definitions of autonomy to be used in a clinical context (Dove et al., 2017). Nonetheless, relational autonomy is relatively uncommonly invoked. Some authors, including Edward S. Dove, an ethicist and legal scholar at the University of Edinburgh, have hypothesized that the continued emphasis on traditional autonomy is because this definition entails comparatively simple legal responsibilities; by contrast, a relational definition of autonomy, containing multiple stakeholders who can all contribute to medical decision-making, would be difficult to square with the existing legal system (Dove et al., 2017). Traditional autonomy's role in the medical (as well as the legal) paradigm may also play a role: clinicians and care workers may be overworked, unfamiliar with individual patients and/or their preferences, or operating within a system that mandates a particular policy vis-à-vis patient autonomy (e.g. policies that insist all patients personally provide informed consent for procedures, even if they do not want to) (Dove et al., 2017). Further exacerbating this problem may be clinicians and care workers, who, in advocating for the traditional form of autonomy, may paradoxically prevent the patient from exercising free choice: for example, a patient wishing to allow a family member to decide a treatment for them, or preferring not to be informed of a diagnosis, may be blocked from exercising these wishes in the name of "autonomy" (Ells, Hunt, & Chambers-Evans, 2011). While most healthcare settings will (at least in theory) allow patients to waive their right to informed consent, historically, patients who preferred for family members to take the lead role in medical decision-making have often encountered substantial resistance from their care team (Gordon, 1996). Today, more clinicians recognize the value of shared decision-making and patient-directed information sharing, indicating a "relational turn" in thinking about autonomy; however, many theorists of relational autonomy disagree about how to define or operationalize the term, instead framing it primarily in opposition to traditional conceptions of autonomy (Gomez-Virseda, de Maeseneer, & Gastmans, 2019). This oppositional approach, while it does highlight the harm that can be done through exclusion of patients' support networks, also runs the risk of flattening some of traditional autonomy's benefits (e.g. limiting paternalistic decision-making, protecting the confidentiality of sensitive information); furthermore, this approach has not yet provided a widely practicable alternative paradigm for decision-making or information sharing (Gomez-Virseda et al., 2019).

In the context of this study, questions of autonomy often take the form of decisions about information sharing; i.e., with whom do AL residents want health updates shared, and how would they like these updates to be provided. While deciding whether and how health information is shared may not be the same kind of choice as deciding whether or not to undergo a bypass surgery, the relative push and pull of traditional and relational concepts of autonomy are equally applicable, as are the challenges of operationalizing any non-traditional conception of autonomy. For example, a sick or hospitalized resident wishing for their own medical updates to be shared with peers may find that there is no mechanism in place to share this information within AL, because health information is habitually from residents withheld due to privacy concerns (as discussed in Chapter 1). A wish to disseminate personal health information may in fact reflect the resident's concern for others in their community (e.g. peers who may be concerned by their absence), and attempting to share this information, assuming that the resident had decision-making capacity, could be framed as a personal choice and thus a reflection of the resident's autonomy. However, for staff members focused on a non-relational definition of the self, a wish to involve others in "private" matters, or share any information on topics pertaining to the "personal/individual" realm of their health, may seem inappropriate or difficult to understand.

Relational autonomy thus provides us with an alternative understanding of autonomy, one that more fully reflects the patient's lived reality and context. As a result, it is a particularly useful concept in the context of AL, where residents may not be able to make decisions independently, and where sharing information for social reasons is as important as sharing information for decision making. Yet it is also worthwhile to generalize the concept of relational autonomy to other settings. Does a relational definition of autonomy only benefit people who are in some way dependent on others? How would this definition of autonomy change medical care (or decision-making in general) if it were applied to all people, regardless of their ability to live independently? Furthermore, given human interconnectedness and interdependence, is the idea of "living independently" even a relevant or meaningful one? These are the questions that the ethics of care seeks to answer, and an analysis of these questions will further inform how care in AL can be adapted to more fully reflect residents' needs.

Beneficence, Ethics of Care and "Completion of Care"

Earlier in this chapter, HIPAA was presented as upholding the duty of beneficence, as the healthcare providers responsible for maintaining patient privacy according to HIPAA are (ideally) doing so to provide for the patient's needs and best interests. We might expand this understanding of HIPAA as upholding the duty of beneficence by claiming that privacy practices such as HIPAA are intended, in their most abstract conception, to *provide care* for the patient. What does it mean to provide care? Eva Kittay, Distinguished Professor of Philosophy at Stony Brook University and one of the founders of the field of care ethics, has defined care as "a labor, an attitude, or a virtue," with these three attributes defined respectively as "the work of maintaining others and ourselves when we are in a condition of need," "a positive, affective bond and investment in another's well-being," and "a disposition manifested in caring behavior" (Kittay, 2011a, pp. 52-53). As such, upholding patient privacy through HIPAA may be framed (again, ideally) as part of the "labor" or "attitude" of caring for patients.

The ethics of care is an ethical framework developed in the 1980s, which seeks to foreground the experiences and perspectives of care recipients and caregivers, and in turn to emphasize the extent to which all people are both givers and recipients of care (Kittay, 1999). Eva Kittay, an early theorist of care ethics, notes that "[d]ependency is inescapable in the life history of each individual" (Kittay, 1999, p. 29), not only at the beginning and end of life but during periods of illness and incapacity that can occur at any point; even individuals who appear "independent" are still, in various ways, dependent on (or interdependent with) others. Kittay, however, chooses primarily to engage with the "clearest cases of dependency" (Kittay, 1999, p. 30), e.g. disabled people and dependent older adults, in hopes that these cases will best illuminate how care should be provided under all circumstances.

How can the ethics of care be applied to the question of privacy regulations? If, as suggested earlier, enforcing HIPAA is intended to benefit the person being cared for, then we might characterize this behavior as an effort to provide care. It is, of course, worth noting that enforcing HIPAA may not, in practice, even be intended to benefit the patient or resident; caregivers may restrict the flow of information out of concern for litigation, unthinking adherence to rules, attempts to minimize their workload, etc. Yet if we assume the best intentions on the part of the caregiver, and argue that they truly believe that restricting this information is in the patient's best interest, these good intentions still do not necessarily mean that care is being provided. Nel Noddings, a scholar of education and early theorist of care ethics, makes the argument that care is distinct from the caregiver's intentions and from the outcome of the care (or attempted care) when she notes that, in order for care to take place, it must be "completed in the cared-for" (Noddings, 1984). In other words, care that is not perceived by the recipient as care should not be "counted" as such, regardless of the caregiver's intention, and regardless of the externally observed result. Noddings writes,

> When I care, my motive energy begins to flow toward the needs and wants of the cared-for. This does not mean that I will always approve of what the other wants, nor does it mean that I will never try to lead him or her to a better set of values, but I must take into account the feelings and desires that are actually there and respond as positively as my values and capacities allow (Noddings, 2005).

Such an attitude towards care is, in a sense, consequentialist: the ethical valence of an act is determined not only by the caregiver's intentions but the extent to which these intentions can be reconciled with the wishes of the cared-for. Eva Kittay uses this consequentialist approach to care to assess whether extreme, harmful, or "unnatural" treatments devised with good intentions (e.g. using a combination of medications and surgeries to ensure that a severely disabled child would remain "forever small" and in her parents' home, as occurred in the case of "Ashley X") can in fact be considered care (Kittay, 2011b). Kittay determined that, in Ashley X's case, the parents' decision could not be considered care, in part because their daughter would not register it as such (i.e. the care was not "completed"). This assertion necessarily complicates any intervention undertaken on Ashley's behalf, since based on Kittay's description it seems unlikely that she would be able to register any action as care, at least in a way that could be detected by outside observers; furthermore, a claim that the cared-for must be able to perceive an action as care would carry the problematic implication that, for example, operating on an anesthetized surgical patient would not "count" as care. Nonetheless, the argument for "completion of care" powerfully argues for the importance of the cared-for's perception over the caregiver's intention. As Kittay notes,

> Good faith does not guarantee that the actions are in fact caring ones. I may intend to care for a parched plant by watering it, but if, unbeknownst to me, the glass of clear liquid I pour in the plant contains vinegar, not water, most would agree that, despite my good intentions, I have failed to care for it (Kittay, 2011b).

The situation Kittay describes has obvious differences compared to the one facing AL residents, but the analogy lies in the caregiver's (possibly erroneous) belief that they are acting in the recipient's best interest.[2] Herein lies the difference between the otherwise similar concepts of beneficence and ethics of care: while to be a beneficent caregiver requires only to act in what one believes to be the cared-for's best interest, truly providing care, per Kittay's framework, additionally requires the cared-for's acceptance of it as care. In Kittay's "forever small" case, the evidence suggesting that the parents did not act in their child's best interest is mostly theoretical, since the child could not describe or indicate her own preferences. AL residents do not have this problem, except in cases of profound dementia; they can, in most cases, articulate how they prefer to be treated, and thus provide an idea of what they do and do not conceive of as care. Yet in the literature described in the previous chapter, it is clear that at least some residents dislike the

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[2] Of course, not all AL caregivers may actually believe that restricting information sharing is in residents' best interests; they may simply refrain from sharing information for other reasons, e.g. workplace norms, concern about losing their jobs, etc. However, for the purposes of this argument, it is most pertinent to ask whether, even if AL staff are acting out of purely resident-focused, beneficent intentions (i.e. what might be considered the best case scenario), their behavior should still be considered care.

restriction of health information and view it as harmful. Thus, at least for these residents, this practice cannot be considered care, regardless of the caregivers' intent.

One might respond that residents' dislike of a practice does not prevent it from being care; a patient having their blood drawn, for example, might dislike the experience but still "receive" this act as care. However, this analogy does not hold up; most adult patients recognize the need to have their blood drawn and the purpose it serves. The need for HIPAA in the context of AL, however, is more nebulous and thus may be perhaps less apparent to some residents. Furthermore, even if most residents recognize the benefits HIPAA provides in an abstract sense (e.g. preventing the dissemination of sensitive information to strangers), these benefits are still counteracted by a significant number of harms specific to the AL setting, most significantly a sense of alienation from peers and a diminishment of social relationships that can significantly decrease quality of life (as discussed in the previous chapter). Of course, some residents likely do prefer that their medical information is not shared, even under the specific circumstances under consideration here (i.e. updates on the condition of a sick or hospitalized resident); one such resident, Shirley, will be discussed in the next chapter. Perhaps, then, the real question to ask about health information sharing is not *do all residents experience the current paradigm of health information sharing as harmful,* but rather *if some residents experience the current paradigm as harmful, is this sufficient justification to explore alternative options?* As Noddings notes, while caregivers still may disagree with the cared-for and attempt to guide them to values that they (the caregivers) see as better, this process must still account for the cared-for's preferences where possible—a bidirectionality that is not seen in current, one-size-fits-all AL privacy practices. Thus, even if some residents accept current AL practices, this acceptance does not change the fact that AL privacy practices fail to respond to the variety of resident needs and wishes. As such, it is hard to justify current privacy practices as care within the ethics of care paradigm, thus highlighting the ethical importance of developing alternative health information sharing options.

Ethics of Care Meets Relational Autonomy

The ethics of care calls for caregivers to develop a "transparent self," one in which, at least in the context of caregiving, "[t]he perception of and response to another's needs are neither blocked out nor refracted through our own needs" (Kittay, 1999, p. 52). A person who has made themselves "transparent to the needs of others" (Kittay, 2011b, p. 51) does not superimpose their own wishes or values onto the people they are caring for. In the context of AL, being "transparent" would imply treating residents as individuals, and recognizing that their preferences may not conform to an expected norm. Relational autonomy offers a similar concept—namely, the idea that autonomy does not look the same for all people. All individuals are interconnected and interdependent to some degree, but some may leverage these connections more directly than others in their decision-making processes; their doing so does not constitute a failure to exercise their autonomy, and should not be viewed as inappropriate or in need of remedy by clinical staff. Both relational autonomy and ethics of care call for those in positions of caregiving to recognize the needs of the "cared-for"—not as they should be, but as they actually are.

This argument is not made with the intent of eliminating privacy regulations in AL: these regulations do serve a purpose, and it is likely that some residents prefer to know that that strong protections for their privacy are in place. Conversely, this argument is intended to propose that these privacy protections should not be forced on people who do not perceive them as desirable or necessary, based on a caregiver perspective that these protections are what the cared-for "should" want. If care must be received to be completed, then accordingly, caregivers should endeavor when possible to provide care that *will* be received as such. In order to do so, caregivers must understand what the residents for whom they are caring *do* want, need, and value. The following chapter, drawn from observations and experiences in one AL community, will endeavor to provide some answers to this question.

Chapter 3: An Examination of One Assisted Living Community's Health Information Sharing Practices

Introduction

This bioethics study aims to answer the following question: What are the health information sharing practices in AL that help or hinder residents' maintenance of self? As discussed in previous chapters, data exist illustrating the importance of social relationships with peers in AL and the role of neighboring behavior (including staying updated about fellow residents' health); several studies point to HIPAA as an obstacle to this kind of neighboring behavior. However, there is little data examining the specific role of health information in the lives of AL residents. This study thus fills a lacuna in the existing literature by examining how residents seek and obtain health information, what role(s) this information plays in residents' quality of life and maintenance of self, and how AL and federal policies (e.g. HIPAA) affect this equation.

We used data from the End of Life in Assisted Living: Links Between Structure, Process, and Outcomes study (1R01AG047408-01; PI: Perkins); the lay title is Transitions of Life and Care in Assisted Living (TLC). The objectives of the TLC study are to understand how end of life is experienced by AL residents and caregivers, investigate the structure and process of end of life care in AL, and examine how the conditions of AL life shape end of life care and affect resident experiences. These objectives are to be accomplished by collecting and analyzing several sources of data: field note observations of the AL setting, semi-structured interviews with focal residents, staff, and family members, and health assessments administered to focal residents every six months for up to two years. A total of seven AL communities are included in the TLC study, spanning two consecutive waves of four and three communities, respectively. These communities encompass different categories of licensure (ALC versus personal care home), payment models (with or without

Medicaid waiver use), ownership (independent versus corporate), location, size, and income level. Communities were each studied for a total of two years, allowing enough time for the research team to establish relationships with residents and staff, as well as observe changes in the AL over time.

One ALC from the first wave, which we will call Parkside (a pseudonym) offered an opportunity to examine privacy in the context of AL. TLC study research staff had observed conflict between social activities in AL and privacy regulations, prompting questions about how privacy interacts with community life in the AL setting (Vandenberg et al., 2018). Parkside is a large (100+ beds), corporate-owned, urban ALC whose residents are primarily white and upper-income. Parkside's status as an ALC means its population has, on average, greater medical need, and is thus well suited for a study examining health information sharing in the AL setting. Additionally, Parkside's large size allows for a wide variety of resident, staff, and family perspectives, and provides opportunity for different attitudes and viewpoints to be described and characterized.

Methods

Our method was thematic analysis (Braun & Clarke, 2006). Using the data management and visualization software NVivo12, we began by searching a data corpus comprised of all researcher field notes and memos and all interview transcripts from Parkside to assemble a data set encompassing the topic of social relationships and privacy. The goal was to identify as many passages as possible relating to aspects of privacy. To do this we constructed a list of search key terms and synonyms that might be found through an NVivo search: privacy, confidentiality, HIPAA, PHI, EMR, rules, regulations, chart, medical record, health record, wellness file, medical information, disclose*, withhold*, death communication, death notice, memorial notice, chow club, resident council. The topics of death communication and notices were selected because these topics had been previously identified as areas in which health information (i.e. deaths) was being shared publicly. The last two items (chow club, resident council) were selected as settings where residents had conversations about a wide range of topics including medical issues. NVivo settings were also adjusted to include synonyms for all terms. Relevant items were coded under the NVivo node "Privacy." Additional data were gathered by examining field notes and those interviews that had been coded (about 20% of all interviews) with related codes from the Transitions of Life and Care (TLC) code book: "Regulations," "Facility-level contexts," "Health transition," and "Care-process." These codes referred, respectively, to extracts discussing AL policies and rules; norms within the Parkside community; resident experiences with health changes; and resident and caregiver/family experiences with receiving, providing, and witnessing health care; these codes were selected for their relevance to the overarching research question. Efforts were made to include as many potentially relevant passages as possible. Again relevant items added to the node for "Privacy." When this data set was completed, it included 220 extracts from 124 sources.

Following the compilation of this data set, the extracts that had been collected were printed out and open coded (Charmaz, 2014) on paper separately by two different coders (author and mentor). This process consisted of examining each extract line-by-line and coding each coherent idea descriptively, while remaining as close as possible to the speaker's original words. For example, a resident observing, "When you live in this neighborhood, you take on everyone's problems" was open coded as "Living in a neighborhood" and "Taking on everyone's problems," Staying as close as possible to the speaker's own language. All open codes were phrased in the form of a gerund, so that all were action statements and therefore compatible with one another. Abbreviations (e.g. "R"=resident; "S"=staff) were used to indicate speaker perspective for each open code. At the conclusion of this open coding process, each extract had between one and five codes describing its content. The two sets of opens codes were compared, discussed, and reconciled before proceeding to the next level of coding. Passages that were not on target were eliminated from the data set.

Following the open coding process, we examined the list of open codes for specific information sharing practices (part 1 of our research question: What are the information sharing practices in this AL?). This was accomplished by physically printing out the list and cutting out (i.e. with scissors and paper) each individual open code, and sorting these codes into categories with other open codes using similar language or expressing similar actions. For example, open codes, "Noticing death notices in the lobby" and "Seeing death notices when someone dies," were grouped together, since they both described the same phenomenon of witnessing death notices (i.e. a printed announcement of a resident's death) in Parkside's lobby. Any other open codes that were similar to these were all placed in the same category, "Seeing death notices." Initially, many small categories similar to this were identified, which were gradually coalesced into four overarching health information sharing practices taking place at Parkside. All data extracts were sorted into these four information sharing practice subcodes. As is critical for thematic analysis, an inductive approach was utilized in identifying these health information sharing practices, rather than trying to fit the data into an existing conceptual frame (Charmaz, 2014).

Having identified the health information sharing practices addressing the first half of the research question, individual extracts were again analyzed to assess whether they helped or hindered maintenance of self, in keeping with the second half of the research question. Within each practice, extracts were coded as helpful, hindering, neutral (i.e. a simple description of a practice, with no positive or negative valence attached to it), and occasionally equivocal (i.e. a resident expressing that a practice had both positive and negative elements). Again bearing in mind that researchers are at risk of projecting their own values onto classifications of valence, these valence codes were assigned based on the terms in which the speaker themselves discussed the topic. For example, death notices were a topic that elicited positive responses from some respondents but negative responses from others; as such, some descriptions of death notices were coded as helpful and others as hindering, based on the nature of the speaker's response.

Having now identified health information sharing practices and the valence of extracts within each practice, each coded passage was examined in a line-by-line fashion to identify what about the practice was helpful or hindering to maintenance about the self, using gerund descriptions.

Finally, the gerund descriptors were analyzed across categories for similarities and re-grouped across categories into overarching themes, each theme representing a "patterned response or meaning within the data set" (Braun & Clarke, 2006). By reexamining the data, as well as its organization into health information practices and sub-practices, and the valence of these practices, we located and developed five themes that each shed light on distinct aspects of the research question. Utilizing thematic analysis allowed for the identification of these themes to take place as an iterative process, in which data were continually categorized, examined, and re-examined, with the central focus remaining on how these data answer the research question.

Results

Our initial analysis revealed four health information sharing practices at Parkside. These practices reflect four distinct ways in which residents, staff, and family members interacted with health information within the Parkside information:

- *Conversing about health* (learning and sharing health information through a language-based exchange)
- *Obtaining health information through observations in the environment* (learning health information through nonverbal, experiential, and visual cues)
- *Using health information* (taking action based on health information, e.g. visiting sick peers)

- *Maintaining privacy* (declining to share health information, or avoiding information exchange).

Each of these practices encompasses a range of behaviors, which indicate different ways in which members of the AL community engaged in the practice.

The category of *Conversing about health* includes conversations among peers and staff about changes in residents' health, including the speaker updating others on their own health. Residents discussed their health with each other and staff members, while staff sometimes also conversed about residents whose health was declining. Conversations about health could take the form of more everyday occurrences (e.g. medical appointments, chronic conditions) and discussing how these occurrences affected daily life—for example, noting that a friend's prostate cancer treatment had led to bladder damage and repeated hospitalizations. However, resident deaths were also a significant topic of conversation. Although Parkside does have a policy for formally announcing deaths (as will be discussed shortly), word of mouth often preceded these formal announcements.

Obtaining health information through observations in the environment represented another major way in which people learned about changes to residents' health. Residents described observing sick and declining peers in public spaces, as well as peers acting out in a way that was noticeable and indicative of worsening health and mental status. Residents also noted that peers would disappear; this absence itself was seen as an indication of decline because it could signify illness, hospitalization, or death. On some occasions, residents would be exposed to staff conversations about death or illness in public spaces, as in one case when a resident discovered another resident had died after hearing two CNAs discussing it in a public area. Staff also occasionally disseminated information about illness in other ways, including one case when a whiteboard outside a resident's room was used by staff to record updates in the resident's condition, including notifications that she had lost her hearing aids. Data from a field note excerpt indicated that the message on the board said, "[She is] on new meds. Hope it will stop the wandering." Additionally, many residents and staff made reference to "death notices," Parkside's official way of notifying residents of a peer's death. These notices consisted of a rose and the deceased resident's photograph, as well as dates of birth and death; they were typically placed in the Parkside lobby shortly after the resident died as a way of formally announcing the death to the community.

Using health information was information sharing in action. It took the form of practices intended to benefit sick peers. Some residents, upon learning that a peer was sick and confined to their room, would visit them there, write them cards, or bring food to their room. Others encouraged fellow residents to engage in these acts as well; Frank, a resident, former minister, and volunteer leader of religious services at Parkside, publicly announced that a peer was very ill, and encouraged the other residents to pray for her recovery. In addition to residents, staff members also acted on health information: Parkside's official policy mandated staff members to visit hospitalized residents every 48 hours for the duration of their hospitalization. Though the extent to which staff adhered to this rule was unclear, such activity, when it occurred, was a way of exchanging more health information through conversation, observation, and reporting.

Maintaining privacy represented an alternative approach to health information in AL, one in which information was not shared, either due to personal preference or to privacy regulations (i.e. HIPAA). In the first case, a few residents simply chose not to share their own health information with peers, based on their own preferences. In the second case, health information such as resident hospitalizations or illnesses was withheld because staff knew this information was protected by facility policy and federal law. As a result, staff members, when asked for updates about residents' health status, would generally decline to answer, with some staff instead offering to convey the questioner's concern to the sick resident. (It is important to note here that only healthcare workers are subject to HIPAA; thus, residents could and did discuss their fellow residents' illnesses, but staff members reported that they were not allowed to do so.)

Having identified these four primary themes that categorize information sharing, we will now turn to subthemes we identified across these categories. These subthemes illustrated how health information sharing practices at Parkside shaped resident maintenance of self. Themes that predominantly contributed to maintenance of self ("helping") were defined as those that allowed residents to use and maintain their personal resources (skills, relationships, psychological resources) in a way that positively affirmed these resources. Themes that detracted from maintenance of self ("hindering") were defined as those that did not allow residents to maintain their personal resources and/or actively prevented the use of these resources. One theme, which contained both helping and hindering aspects, was labeled as equivocal.

Theme 1: Providing information about shared life stage and health circumstances builds community

For many Parkside residents, illness and declining health were facts of daily life. For residents coping with aging and chronic illness, conversations about these challenges were a way of bonding over shared circumstances. One researcher noted in field notes, after conversing with several different residents, that all of those residents had undergone (or were scheduled for) some kind of medical appointment one day when she was in the field observing. These experiences functioned as a common bond and a topic of conversation for the residents going through them. Dora, a high functioning resident and former nurse, expressed the value of these shared experiences with fellow residents:

> [I]f you say you got to go to the bathroom three times in 10 minutes they [other residents] know. You know you're all probably on Lasix or something. They understand. You can say most anything you want to most of these people.

Dora, who further expressed that she felt like fellow residents were more like family than like friends because she could share anything with them, illustrated the value of sharing health challenges as a way of building relationships between peers in AL.

For other residents, health information—particularly information about residents who were declining or deceased—served as a way for residents to ponder their own decline and death. When a resident unexpectedly collapsed and died in Parkside's dining room, and staff members tried unsuccessfully to revive him, another resident who witnessed this scene noted that seeing CPR up close reinforced her own choice to sign a do-not-resuscitate order. The experiences of peers served as "food for thought" in more everyday cases as well: a different resident, commenting that a friend had just been hospitalized for a UTI, said that she would not want the same thing to happen to her. In both cases, information about peers' health prompted residents to consider their own choices and preferences. Scott, the Parkside executive director, offered a similar explanation for why Parkside displayed death notices (a relatively new practice): "[I]t gives them the opportunity if they have any questions they can come to us." Framing the death notices as a way to elicit and respond to resident inquiries, Scott also reinforced that health information can prompt thought and questions.

While providing health information sometimes prompted questions, it also served in some cases to promote community engagement among residents. Some residents, upon learning that peers were sick, visited them in their rooms, while others took on leadership roles and invited community members to send prayers and good wishes to sick peers. Frank, who was a high-functioning former minister and volunteer leader of Parkside's Sunday morning church services, described prayer for sick residents as both a personal and social activity:

> I usually acknowledge it and pray for that person and their family on Sunday morning [during services]. The friends at my [dining] table, we prayed for somebody the other day, and I prayed aloud. That's pretty unusual….They really appreciated it, and so did the person we prayed for.

For Frank, praying for sick residents was part of his weekly routine; however, the unusual additional step of praying with his table mates was a source of confidence, as he recognized that he was able to help both his peers at Parkside and the sick resident they prayed for. An excerpt from field notes illustrated another occasion involving Frank:

> Frank turned off the music, took up the microphone, and welcomed everyone to the service….He also asked that people pray for [a fellow resident], who they had known as such a strong person that her strength might return because she was now lying in her room unable to move.

Frank's speech at the chapel service provided valuable information to his peers; however, it took the additional step of encouraging compassion through a specific step that fellow residents could take (i.e., praying for the sick resident). For Frank, medical information provided a springboard to encourage compassion in others, while also facilitating his own maintenance of self as he affirmed his ability to help fellow residents.

Parkside residents' exchange of information about one another's health appeared to be a way to bond over shared health issues and the difficulties of their life stage. Environmental cues such as sick peers and death notices also prompted these conversations, and even stimulated residents to consider their preferences at end of life. Engaging with health information also kept residents informed of who was sick and in need of support; some residents took on roles to help provide this support. These practices were important ways to ensure maintenance of self through drawing upon different types of personal resources (e.g. human capital, psychological capital, and social capital) to cope with the challenges of aging and of living in an aging and declining community. Within the context of assisted living (see Perkins et al., 2012), human capital refers to personal resources such as knowledge, skills, personality, mental and physical capacities, and physical appearance. Psychological capital includes religious faith and spirituality, sense of hope, resilience, and sense of personal self-efficacy as well as cultural strengths such as racial and/or ethnic pride and a sense of collective tradition and community. Social capital includes personal resources and status characterized by group membership and social or interpersonal ties. These types of capital all can be brought to bear in helping residents navigate challenges specific to the AL setting.

Theme 2: Avoiding health information disclosure or providing incomplete information leads to frustration and further questions

Further indicating the salience of health information in the lives of Parkside residents, many residents sought information about peers who were sick, absent, or hospitalized. However, presumably due to HIPAA (though also perhaps to a personal sense of decorum or perception of appropriate behavior), Parkside staff could not provide much information, leading to frustration among the resident population. In some cases, staff also avoided disclosing information beyond what would be subject to HIPAA. Restricting the flow of information in this way seemed to reflect an institutional culture of privacy, one in which information was not shared out of (possibly a combination of) misunderstanding the boundaries of HIPAA, avoiding conversations that might be uncomfortable for the staff member(s), and/or withholding information that was felt to be harmful to residents. This lack of information at times hindered resident maintenance of self; residents reported feeling infantilized, or feeling that their concerns were irrelevant, because they were not provided with key information about their peers.

The lack of information provided by the Parkside staff and administration was a frequently cited source of frustration for residents and family members. To some residents, this lack served as proof of their low status within the home. Louise was one resident who expressed this attitude:

> They don't tell you anything….I can't quite understand that because those of us who…have gotten close to people, or who don't put ourselves in the category of an old person ready to die. It seems to me that's where they *[laughter]*—how they wanna classify us most of the time, instead of just being an individual with certain developments and likes and dislikes. Tryin' to help us through by explaining things or telling us things, but they just don't.

To Louise, the absence of information from Parkside staff was a frustrating barrier to her gaining needed updates about the health of the residents she was close to. However, it was also an indication of condescension: at Parkside, she had been categorized not as an individual, but an interchangeable "old person ready to die," who was thus not entitled to the same information or consideration that she would previously have received.

Although Louise described the experience of being denied information, she offered little speculation on why staff do not share health updates: "they just don't." By contrast, several Parkside family members, expressing similar frustration about the limitations of HIPAA, mentioned it specifically by name: Katie, whose mother was declining and confined to her room, said, "I don't think they are [aware of her condition] unless they stop by [her room]. Nobody's gonna tell 'em anything. They can't 'cause of HIPAA laws, right? Yeah." Using language almost identical to that of Louise, Katie agreed that nobody tells residents anything; unlike Louise, however, Katie specifically attributed this lack of information to HIPAA. Sandra, another family member, made a similar comment: "I don't know if it's HIPAA or whatever rules. They don't talk about anyone else's health or what's going on with them." A third family member, Jennifer, yet again attributed the absence of information to HIPAA, but went further by identifying how this lack was harmful to residents when one of them was dying and therefore on her way out of the community:

> [S]ometimes, the HIPAA and the privacy stuff kinda gets in there, and that kinda adds to people not knowing what happened, or not knowing what's wrong with someone, or not knowing that someone is actually about to die, and so they could actually have said their goodbyes, or known, or said, or whatever…I think that leaves people just feeling a little bit cheated or something.

Jennifer, analyzing the feelings of her mother and other Parkside residents, pinpointed HIPAA as the source of missed opportunities for resident relationships: residents' ignorance of who was sick or dying prevented them from saying goodbye or taking any other actions they might deem appropriate at the end of their peer's life. Being unable to learn this information left residents feeling "cheated" or unimportant; meanwhile, opportunities to learn more (e.g. by going to visit sick peers, as Katie described) were limited if the sick resident was hospitalized.

Given the lack of information coming through official channels, residents seeking updates on their peers' health sometimes turned to alternative sources. Residents updated one another on peer health through stray comments (One resident, Janine, spotting another resident near the elevator, loudly commented, "He's been better!") or through gossip, which some described as endemic. Jack, discussing how health news spread at Parkside, said that most residents found out about deaths through "gossip. Real gossiping," and added "We're a very gossipy place here. I find it very unpleasant. Otherwise, it's a nice place to live, but that's an unpleasant part of our society." David, a care worker, echoed this assessment: "[E]verybody's nosy, and everybody's talking about it," when residents reached end of life. In addition to word-of-mouth sharing, residents sought and guessed news about peers through environmental cues. Shirley interpreted a series of signals in the Parkside environment as indicative of death:

> You'd see the family coming and going. They have teary eyes. You know something has happened. Then if you don't see a person for two or three days you begin to ask questions. What happened? Then they would tell you that way….[If] something were to happen to me, you would probably begin asking questions about me and my state, what happened.

Donald similarly investigated the environment for clues when residents disappeared. Asked if any residents had died since he moved in, he responded, "I'm sure they have. I couldn't tell you which ones, but across the hall they're remodeling the apartment. That means that the person is gone. I don't know whether they died or transferred to another place." Whether seeking information through word of mouth or through clues in the Parkside setting, residents found alternative strategies to learn (or make educated guesses about) their peers' health statuses. These strategies provided incomplete information at best, and—as in the case of gossip—were distasteful to some. However, Shirley's comment that "you would probably begin asking questions" about a resident who disappeared illustrated this challenge: unreliable or incomplete information, despite its frustrations, still seemed preferable to none at all.

Nonetheless, as described earlier, Parkside staff were loath to share health information, in part due to HIPAA. Furthermore, in some cases this reluctance to provide information actually went beyond the restrictions that HIPAA imposed. When Parkside's executive director, Scott, left his job and was replaced with a new director, field note data showed that one resident, upon learning this information, commented that "everybody just disappears and no one ever tells us." This refrain also came up repeatedly in the context of resident deaths, which are not legally considered PHI. Paradoxically, although Parkside displayed death notices for residents who had died recently, residents felt that these deaths were never discussed. As Tom stated, "They don't make any commentaries other than what's there [the death notices]. They don't make any announcements about nothing." Asked if he would like additional counseling or support around resident deaths, he responded, "I've been wondering about that." Lisa, a resident's daughter, similarly noted that, other than displaying death notices, she had "no idea how [death is] handled" at Parkside. According to Scott, Parkside's executive director, this method of communication was intentional:

> When a resident in the community passes away, we put a little memorial rose and their picture and their date of passing up immediately….'cause we had identified, our residents were getting angry at us….they were frustrated because a resident would pass away and we wouldn't openly announce it to the community….[T]hey used to tell me, "You need to come around and tell everybody." No, that's not the way to do it. It's not. Because everybody grieves in their own way. And just announcing that, that's not something we want to do for anybody. So that's why we decided to do it in a non-open….it's just a very solemn…it's just one red rose in a vase in front of their picture. So I don't know what the best way is.

Scott's comments thus suggested a tension between a desire to satisfy residents' requests for information and a perception that it was inappropriate to provide more than a certain amount.

Scott's comments, coupled with the fact that notification of death is not actually protected by HIPAA, seemed to reflect a sense that information exchange between staff and residents—even when it was not about a "protected" topic such as hospitalization or illness—was harmful, inappropriate, or at the very least suspect. This attitude, which might be termed a "culture of privacy," restricted information sharing even beyond the boundaries imposed by HIPAA. Parkside's culture of privacy made death information difficult to obtain for residents; however, it also affected other aspects of the resident experience, and occasionally led to conflict between residents and staff. In one Parkside resident council meeting—a space intended for residents to self-govern and raise concerns with staff members—Shirley stated that she had been erroneously given insulin when her blood sugar was already low. Ron, the staff member at the meeting, responded that private medical issues could not be discussed in resident council. A similar incident took place at another resident council meeting: several residents expressed concern after a peer fell in his room and staff failed to respond promptly to his call bell. Discussing the meeting with a researcher, Ron voiced anger that the residents "pried" into this incident, and stated that their doing so was a violation of privacy boundaries. While it is possible that Ron's objection to these inquiries was rooted in a zealous or incorrect understanding of HIPAA's limits, the context of both of these cases (i.e. errors committed by Parkside staff) also seemed to suggest that privacy was being used to avoid conversations about quality of care that were uncomfortable for the staff.

The relative unavailability of information—whether protected or not—thus constituted a familiar reality at Parkside. While, as described, multiple residents expressed frustration with this lack, some went further, offering specific suggestions or alternatives for improvement. Frank commented, "One thing I don't like is that they don't tell us when somebody goes to the hospital or how they're doin'. I wish they would publicize that." Patricia offered an alternative idea; asked about how peers know when a resident is hospitalized, she responded, "[T]hey don't tell you much…[I]t's not gonna come out unless maybe a family member or a friend has said they heard it…I was gonna tell [my daughter]. It gets frustrating sometimes. If I'm in the hospital, make sure [three of her close friends] know why I'm in there." Though these ideas reflected two different approaches—a community-wide policy change, versus an individual tactic to ensure friends stayed up-to-date—they both indicated a wish, at least on some residents' part, for health information to be shared more freely. At the same time, these wishes indicated how Parkside's current policy of sharing little or no information hindered resident maintenance of self, as residents perceived the lack of information as frustrating or disrespectful, and felt that it reduced their ability to maintain meaningful relationships with their peers.

Theme 3: Inserting medical information into public space medicalizes the social environment

Even though residents did not usually receive timely or complete information about peers' illnesses or deaths from the Parkside staff, they frequently noticed and responded to health information embedded in the lived environment. This embedded health information included residents who seemed unresponsive, behaved inappropriately, or in other ways appeared visibly in decline. Several residents expressed displeasure at seeing declining peers in public spaces at Parkside. Frank, walking in the Parkside living room and noting several residents slumped in their chairs, commented disapprovingly, "This is a nursing home." Other residents expressed similar feelings about individuals or behaviors they found undesirable. Donald said that in Parkside's dining room "you see a lot," specifically referencing a woman who shrieked and a man who could not speak after having a stroke. Asked if he had made friends since moving in, Donald responded, "I don't want to make friends here in a place like this." Brenda, a family member, reiterated these concerns:

> [T]hey watch this progression, so somebody starts to act out in the dining room, typically, making a lot of noise or pitching fits or doing something, and they're all really upset about it. They're really mad. This is really awful….I think it makes them feel like they're living in an asylum or something.

The feeling of "living in an asylum" seemingly underpinned Donald's wish to avoid making friends in "a place like this," where residents were sick, declining, and unable to perform socially acceptable behavior. Louise articulated this feeling in more detail. Complaining that many residents at Parkside were sick and that she did not want to eat in the dining room with residents who needed feeding, Louise indicated that although she felt denial of death at Parkside was a problem, she wanted lunch to be a time where she could be social with her friends and not reminded of end-of-life issues. Louise noted that residents who needed caregiver assistance with eating already had a special table designated for them, and felt that those residents should be restricted to eating there. Louise, Donald, and Frank all seemed to feel that declining residents' presence "medicalized" Parkside's social spaces and thus made them less appealing. Other residents found the presence of declining peers distressing, but for more personal reasons. Eleanor described her sadness when she visited and spent time with a friend who had been "bright as a dollar" when Eleanor arrived at Parkside, but was now nearing death. Dora shared a similar experience when she encountered a friend from earlier in life, who was now a fellow resident at Parkside. The friend was "kind of out of it. Didn't know who I was," and Dora described the experience as "[n]ot comforting at all….It was quite a shock to see people go that far from one side to the other." For Eleanor and Dora, the presence of declining peers also served as an unwelcome reminder of death, but with an additional layer of sadness or distress upon witnessing this fate happening to people they felt close to.

Less extreme examples of health information permeating the social environment could also be perceived as excessive. Administering medications in public versus private spaces was a source of ongoing debate; Parkside administrators historically had administered medications in the a designated room upstairs at designated times, with residents visibly lining up in the corridor to wait their turn, and sometimes also pulled residents into quiet adjoining rooms during lunch to give medications, including insulin shots. However, Parkside was in the process of switching to a system where staff delivered all medications to resident rooms by cart. Resident opinion was divided on this change. A nurse noted in resident council that medication technicians sometimes interrupted residents at lunch for injections, even though the residents asked them not to, a statement that

Kathy, a listening resident, agreed with. Patricia added that she didn't like going into the library and seeing people getting their blood drawn. However, some residents expressed concern that the cart system would lead to confusion and missed doses, while another resident said that she would prefer to go into the library (a small room that was usually empty) for injections since it meant she could get back to lunch sooner. For the residents and staff negotiating this transition, the desire to preserve resident privacy and avoid medicalizing social space with insulin shots and blood draws still required balancing with residents' wish for convenience and social interaction. While receiving medication in public places clearly medicalized the social space of Parkside, to the objection of some residents and staff, taking residents back to their rooms during lunch for injections (which took much longer) led to a different kind of "medicalization," in which resident social needs were made subordinate to their medical needs. What residents seemed to want most was an environment that met their medical needs without causing these needs to intrude into their social, lived world. However, as illustrated here, opinions differed among both residents and staff about how to achieve this goal.

Environmental cues, like declining residents and public medication administration, were not the only way social space was medicalized at Parkside. Conversations about medical topics, although sometimes a way for residents to bond over shared challenges, could also become excessive or burdensome when they involved oversharing about illness and death. Sara, one of Parkside's activities directors, articulated this tension:

> I think that everybody just overshares….I think it's okay to a point of bonding like why are we both here kind of thing. Then it gets to be a little bit too much when you know what appointment someone is going out for and why they're not down at lunch and things like that.

As Sara indicated, though, there was a continuum between bonding and oversharing, and not all residents agreed on the point at which bonding over medical challenges became a burdensome intrusion into daily life. Discussing the agenda for an upcoming resident council meeting, Martha, a resident, said, "We can't spend our time talking about everyone's health problems," to which another resident responded, "People should feel free to talk about it if they want to." As illustrated here, conversations—in resident council and in other spaces—represented another way in which medical information could permeate Parkside's social spaces.

Sara summarized how conversations among both residents and staff contributed to the medicalization of social space. She noted that staff often divulged medical information about other residents, often as an excuse for being late or other reasons; residents would then spread this information to one another at lunch. Sara added that residents, rather than bonding over gender, ethnicity/race, religion, or geography, bonded over their functional status and medical situations. This type of bonding clearly had value as a source of support for residents experiencing illness and decline. However, using health status as a means of social bonding also meant that residents medicalized their own environment, making it hard for them to discuss or bond over other topics. This conversational emphasis combined with ever-present environmental cues reminding residents of illness and decline to make the medicalization of Parkside's social space even more profound. For residents seeking a normative social environment, this medicalization hindered maintenance of self. The omnipresence of health information in the environment (in the form of visibly sick and declining residents, medication administration in social spaces, and social interactions that placed health front-and-center) threatened the self-concept of residents wishing to see themselves as characterized by their individual attributes, rather than their age and vulnerability.

At the same time, however, most Parkside residents undeniably were experiencing health challenges, and many were nearing the end of life. Declining peers, frequent deaths, and death notices were such a common and central part of life in Parkside that one resident, asked what had been happening lately in the home, responded, "People dying." Death notices served as a kind of shorthand for death: one resident, speaking at resident council, reminded others that life is short and "[n]o one wants to be on that photo," referring to the death notice memorial plaque. Given the inescapable reality of death and decline in a setting designed to accommodate people up to the end of life, several residents expressed that Parkside did not do enough to discuss death. Louise, who considered activities such as bingo frivolous and did not participate in them, summarized this feeling: "They are lacking on what helps old people. This is not a party atmosphere." Louise and Lisa, a resident's daughter, felt that Parkside should offer classes about what to expect in assisted living, while Dora felt that it would be "nice to have someone here that you could go to to talk of something that was bothering you and including death." These residents illustrated the frustration of living in an environment where death is both unavoidable and mostly unacknowledged, and expressed a wish to openly address the realities of aging and decline.

Theme 4: Negotiating privacy boundaries in health information requires compromise between residents and staff

Parkside's staff members, like its residents, were members of the community, who formed close relationships with residents, stayed well-informed about their health issues, and were invested in their well-being. Parkside policy was to have staff members visit hospitalized residents every 48 hours, and staff found out quickly when residents were sick: Michael, a housekeeper at Parkside, updated researchers about one hospitalized resident's condition several times. Residents also bonded with staff members over their shared concern for sick residents. In a mixed group of residents and staff discussing the illness of a resident named Linda, one of the residents noted that Linda hadn't eaten in weeks, and Ron, a staff member, expressed concern and said he would go check on her. Bonds between residents and staff also led some staff members to share news of deaths with residents, as Dora described: "Once in a while…one of the care managers will [tell you] and it's not something you inquired about. They just thought you might be interested to know." Some residents also looked staff members as resources or confidantes for health questions; Shirley felt uncomfortable discussing medical issues with peers ("that's private") but shared these concerns with one of her care workers.

> My caregiver at night, I had been coughing a lot, she said, "Shirley, you need to go to [the hospital]. I had her call the ambulance….Sometimes it's good to listen to other people….They couldn't find anything wrong with me. It gave me a sense of relief that I followed her advice[.]

At the same time, staff members were sometimes the recipients of residents' care and concern. Teresa, a Parkside resident, described to researchers two staff members she was concerned about, both of whom had seriously ill children they were caring for at home. Teresa, who seemingly served as a confidante for these staff members, stated, "When you live in this neighborhood," indicating Parkside, "you take on everyone's problems."

Yet despite the close relationships between residents and staff, negotiating the boundaries surrounding HIPAA posed an inherent challenge. Staff legally could not share this information, but felt frustration about their inability to update residents. Nina, a staff member, expressed this frustration: asked if staff members had residents asking them about their peers, she said they did, and added:

> We can't expound on it…We tell them we let the other residents know if they're asking about them and concerned about them, and we just try to put it in our own words, make it seem not harsh, but we can't tell them personal information…I know it hurts them. Especially this is the last place most of them—it's their friends. The last set of friends, so it's probably upsetting…Some are real down.

For Nina, the obligation not to share PHI represented a painful conflict with the wish not to hurt residents. Nina tried to soften this conflict by offering to pass on messages of concern, a practice that her colleague Ron also used. Ron, asked about the same situation, responded,

> Yeah, they'll ask you, but you have to keep it professional…[I]f they say, 'He's in the hospital, or is he in his room?' I'll say, 'When I see him, I'll let him know you were asking,' but you don't go into the details of it.

Interestingly, Ron, offering a similar explanation at a different time, said that he would tell residents when their peers were hospitalized, but would not offer any additional information, suggesting that staff members were not always internally consistent in the amount of information they felt comfortable sharing. Ron, discussing residents' desire to stay updated on their peers' health, added, "The influence…that they have on each other, you'd be surprised," and stated that those with close relationships had better quality of life. By connecting the salience of social relationships with the experience of denying them information, Ron also pointed to the difficulty staff members face in reconciling loyalty to residents and adherence to the rules.

Residents and family members, however, seemed to understand and feel sympathetic to staff members' challenges in this regard. Josh, a resident's son, stated:

> I'm really dear friends with these staff. That's why I wouldn't even think about moving my mom cuz they know my mom. They're like my sisters to me…I know HIPAA rules say they can't tell me everything. I used to get a lot more information, and I'm trying to gather information, but no, I think they're overworked.

Although Josh's efforts to obtain health information were limited by HIPAA, his feelings of concern and care for Parkside's staff led him to feel sympathy for their challenges, rather than annoyance or anger. Some residents also recognized the difficulties staff faced in sharing information. Patricia, asked whether staff shared information about sick peers, responded, "Yeah, they can't say a whole lot, but they can say that they're not feeling well," emphasizing what staff members did do rather than what they did not. Joy said that sometimes staff members even breached privacy boundaries to share information that residents requested: "Caregivers are not supposed to tell us anything now…Well, occasionally they do, but don't write that down because they're not supposed to, and they could lose their jobs if they do." This acknowledgement further indicated the feelings of alliance on both sides: that staff members sometimes prioritized residents' requests for information over facility policy, while Joy felt concerned that admitting this could jeopardize the staff members' jobs.

Close relationships between residents and staff served as a source of support for residents and families, and sometimes for staff as well. These relationships helped resident maintenance of self—both on a practical level, as staff members helped residents with the activities of daily living that they could not accomplish alone, and on an interpersonal or emotional level, as staff members served as confidantes and valued community members with whom residents forged ongoing connections. However, the implicit presence of a "third party"—i.e. federal regulations limiting information sharing between residents and staff—impaired this relationship and caused frustration to both residents (who wanted more information) and staff (who wanted to, but could not, provide it). This restriction thus hindered resident maintenance of self, since residents were less able to utilize these relationships with staff members as a source of support during challenging times such as the hospitalization of peers. Consequently, relationships between staff and residents could perhaps be best characterized as equivocal regarding maintenance of self—while the relationships themselves helped maintain residents' sense of self, restrictions on the relationships hindered it.

Conclusion

In this study, we analyzed data from field notes and interview transcripts collected over two years at Parkside to identify behaviors related to health information sharing, then further examined these behaviors to identify four themes that illustrated the ways information sharing (or the lack thereof) affected resident maintenance of self. We found one positive theme: Conversations between residents about health and illness could serve as a way for residents to bond over shared health challenges, thus building relationships, strengthening psychological capital, and helping maintenance of self. We also found two themes that hindered maintenance of self. Residents at Parkside typically received incomplete or partial information—or no information at all—when peers were ill, leading to feelings of infantilization and frustration. At the same time, Parkside residents inhabited a social environment characterized by medical intrusions by care workers, as well as by residents eager to discuss or overshare medical information. These two hindering themes combined to yield an environment where medical information was plentifully embedded in the environment, yet was at times paradoxically difficult to access. The fourth theme contained both helpful and hindering elements: residents formed positive relationships with staff members, but were challenged in negotiating privacy boundaries that met both parties' needs. Having described these themes, we will next discuss their implications, as well as potential strategies for managing the ethical and practical challenges of health information sharing.

Chapter 4: Toward A New Approach in Health Information Sharing Practices

The themes identified in our study illustrate the complexities of managing health information in a setting that is simultaneously a home, an institution, and a site of health care. AL residents, like many people, often seek to process the challenges of their lives through conversations with peers. Since most AL residents are older adults living with chronic illness, and many are also on hospice, indicating that they are near end of life, health challenges represent a shared circumstance over which residents can bond. Yet this type of discussion is impeded by the fact that residents are not simply living in private residences; they are members of a community and are thus subject to its mores and rules. In the case of AL, these rules (i.e., HIPAA) were originally intended to govern information sharing in traditional healthcare settings such as clinics and hospitals. When applied in AL, these rules make it difficult for residents to maintain meaningful social relationships—or even to follow up on the more casual connections that, as discussed earlier, are still critically important for life satisfaction and quality of life in AL (M. M. Perkins et al., 2013). Residents perceiving a lack in their social relationships—regardless of what form these relationships take—in turn may lack the social capital (i.e., meaningful connections, a sense of fellowship or belonging) necessary for maintenance of self in AL.

Those in favor of maintaining HIPAA regulations as they currently stand in AL might respond that HIPAA provides an important benefit alongside its limitations: namely, it ensures privacy for AL residents. This is a significant claim, since ample literature demonstrates the harms of infringing on privacy in AL (Roth & Eckert, 2011; Zimmerman et al., 2016); in our study, some residents, such as Shirley, also stated that they did not feel comfortable sharing their medical information with peers. Resident concerns about health information privacy are thus an important consideration in reevaluating the balance of privacy and social relationships in AL. Yet as our findings demonstrate, HIPAA actually did little to ensure resident privacy even when it was enforced. Information was constantly conveyed through word of mouth between residents and ubiquitous environmental cues. The use of HIPAA was thus not only frustrating but incongruous: residents were denied information about decline, death, and hospitalizations even as this information was present all around them. The fact that residents sometimes could determine that someone was sick without ever being told—for example, Donald figuring out that someone had died or left when their apartment was remodeled—did not seem to provide the same sense of closure, nor could it ensure the same level of accuracy, as it would if residents were told directly. The lack of straightforwardly provided information also seemed to lead to frustration with or alienation from AL staff, even as residents often retained an otherwise sympathetic attitude towards staff members. The juxtaposition of formal health information restriction with the ubiquity of health information in the environment highlights the distinction between confidentiality and privacy discussed in Chapter 2; while HIPAA may provide for the confidentiality of medical records, and some types of information sharing (e.g., as seen here, when residents asked staff directly about peers' health), maintaining confidentiality cannot ensure an overall experience of privacy, particularly in a communal setting like AL.

This study is the first to specifically examine the ways in which AL community members—a category including residents, family, and staff—share health information. As our results have shown, the way that HIPAA is used in AL is both contradictory and potentially harmful to residents. We thus advocate for an alternative conception of how privacy regulations should be formulated in AL, drawing from relational autonomy and ethics of care frameworks that acknowledge and respect AL residents' status not only as individuals with free will, but as members of a community, who may exercise that free will in ways that emphasize both their interconnectedness and their independence.

Using Ethical Frameworks to Develop a Solution

This study has significant implications regarding how privacy should be conceived in AL from an ethical standpoint; more broadly, it invites healthcare providers both in AL and in other care settings to question whether it is actually the caregiver, the family, or the resident (or patient), whose values are given primacy. Although HIPAA may have been intended to ensure patient privacy, such an intention is moot when patients (or residents) with full decision-making capacity and cognitive reasoning abilities indicate that they do not necessarily prioritize privacy over other values such as fellowship with peers or communication with family. Insisting that HIPAA must be enforced under circumstances where (a) residents suggest or directly state that they dislike this policy, and furthermore (b) residents, paradoxically, have easy access to this information in any case, represents a strong parallel to Eva Kittay's "watering a plant with vinegar" example, in which one's good intentions fail to nullify the harm done (Kittay, 2011b). As Nel Noddings writes, "I need not…be a person who cares only for myself in order to behave occasionally as though I care only for myself" (Noddings, 1984). Providing the example of a teacher trying to convince a struggling student to appreciate mathematics, she notes that this attempt at motivation represents a failure of empathy, and thus a failure at care, despite a wish to do good. "I am not trying to grasp the reality of the other as a possibility for myself. I have not even asked: *How would it feel to hate mathematics?* Instead, I project my own reality onto the student and say, *You will be fine if only you learn to love mathematics*. And I have 'data' to support me" (Noddings, 1984, p. 15). In short, one's intention to provide care, no matter how genuine, cannot be construed as care when it reflects the caregiver's conception of what the cared-for's values or preferences should be, rather than what they actually are. By centering on the theoretical needs or wishes of idealized people rather than the expressed (and divergent) needs of real people, such a conception of care fails to promote flourishing of individuals, not as interchangeable care recipients as themselves.

Both ethics of care and relational autonomy frameworks can be used to demonstrate more appropriate responses to the dilemma of balancing resident privacy and social connectedness. Ethics of care cautions against applying one-size-fits-all frameworks to the complex and deeply personal task of caring for other human beings:

> To be treated as "types" instead of individuals, to have strategies exercised on us, objectifies us. We become "cases" instead of persons. Those of us who are able to escape such situations do so with alacrity, but escape is not always possible, and for some of us it is rarely possible. The fact is that many of us have been reduced to cases by the very machinery that has been instituted to care for us (Noddings, 1984, p. loc1029).

Interestingly, Noddings' description of objectification in the context of care closely matches Louise's description of Parkside caregivers as treating residents like "an old person ready to die…instead of just being an individual with certain developments and likes and dislikes." Ethics of care demands an alternative model, one in which residents *can* be individuals, and have their likes, dislikes, and preferences acknowledged and their care modified accordingly.

Relational autonomy similarly requires an approach in which decision-making is not restricted to one mandated framework; rather, "[r]elational autonomy perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants" (Mackenzie & Stoljar, 2000). In the setting of AL, decision-making may encompass the decision to share personal health information and updates with peers, or to seek input in how personal information is disseminated in other ways, and this decision-making will always take place in the context of individuals' relationships and social context. Health information sharing thus may represent a way to help residents make decisions and consider values (e.g., as in the case of the resident who heard her friend was hospitalized with a urinary tract infection, and concluded that she would not want to experience the same thing), but the choice to share personal health information may also represent a decision in itself, one that aids in maintenance of self and reevaluation of one's personal preferences. As physician ethicists Jennifer K. Walter and Lainie Friedman Ross note,

> An individual's interests are developed in conjunction with others. They are re-described and re-examined during challenging times. Dialogue with others about these interests and choices is not an affront to an individual's autonomy in this relational account. It is, instead, the only way to allow autonomy to fully flourish (Walter & Ross, 2014).

Individuals in all settings, including AL, may thus prefer to make decisions and consider personal values in the context of their social relationships and community. The fact that decisions and considerations made in this way may not always reflect the same priorities as those made by individuals with no input from others does not make one paradigm "better" than the other—and furthermore, the concept that *any* individual's values, decisions, or priorities are ever made entirely alone itself reflects a Western ideal of independence more than a reality. Accordingly, relational autonomy calls for the freedom to acknowledge one's embeddedness in a larger context when making decisions, and further calls for caregivers' recognition that residents may regard this larger context as an important part of their values and their decision-making paradigm.

Ethics of care, then, calls for recognition of residents' individuality, and relational autonomy calls for acceptance of different value systems and the contributions of the larger community in residents' daily lives. But how should these ethical frameworks be applied in order to develop new strategies that maintain both fellowship (i.e. social relationships in the context of a larger community) and individual privacy in AL? Clearly, shifting to an opposite set of priorities in which fellowship is foregrounded and residents are not given the opportunity to ensure the privacy of their medical information would not be an ethical improvement over the current system: despite the importance of fellowship at Parkside (and, presumably, in many other ALs), some residents doubtless value privacy more highly. Although the evidence collected in this study suggests that many residents would prefer to have more health information shared, we cannot assume that all residents feel this way, and cannot ignore the fact that residents will always have different sets of priorities.

Thus, before proposing practical solutions to this challenge, we must first establish the ethical guidelines under which these suggestions will be proposed:

1. Assisted living is a home, a residential institution, and a site of health care, and as such, social relationships and fellowship play a key role in residents' lives. Information sharing policies in AL should reflect this distinction by recognizing not only the value of privacy but the importance of fellowship and relationships with peers.
2. Privacy regulations in AL must also acknowledge the difficulty, if not outright futility, of ensuring "true" privacy in a setting in which (as seen at Parkside) information is often easily accessible through conversation and environmental cues. As such, it is important to recognize that failing to share information publicly will not mean that residents receive no information, but rather that they receive partial or incomplete clues that lead to anxiety and frustration (and, perhaps, misinformation, if clues are misinterpreted).
3. Residents are individuals and will vary in their attitude towards social relationships and information sharing. It is thus critical that any modifications made to AL privacy regulations include the option for customization on a strictly voluntary basis, so that residents can make decisions that reflect their own values. Privacy, although important, should not be prioritized against residents' wishes; conversely, residents who do value privacy very highly should not be forced to surrender it.

A New Advance Directive for Health Information

An advance directive is a document that functions as a way of recording the author's preferences for medical treatment at end of life, and/or designating a proxy decision-maker in the event that the author becomes incapacitated (Childress, 1989). Although originally developed with the intention of specifying medical preferences, an advance directive can be construed more broadly as a way of indicating one's own values at a time when it might be difficult or impossible to communicate these values oneself. Thus, an advance directive—or a document much like one—could be developed as a preparatory measure for any event in which the author could not be contacted easily or is unable to speak to the community for themselves: for example, a hospitalization event for an AL resident. This new form of advance directive—perhaps called a *health information advance directive*, or a *disclosure of information form*[3]—would allow an AL resident to formally record her preferences vis-à-vis health information sharing in the event of hospitalization or moving to a new location such as a new AL, an inpatient hospice, or a relative's home; the AL could then accommodate these preferences.

What would a health information advance directive look like in action? On moving into AL, new residents would be asked to fill out a document indicating whether and how they would like their health information to be shared with the community. This document would first consist of a question establishing whether the new resident *does* wish for peers to be notified and given basic details if they are hospitalized. For ease of operationalizing, this question would be framed as a binary, i.e. either all peers would be informed, or none would be; residents asking that only certain peers be informed would likely not be practically feasible, and would also risk playing into or worsening extant social divisions in the AL community. At this point, residents who indicated that

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[3] Referring to such a document as a health information advance directive would more clearly establish its purpose, i.e., to record preferences (in this case, regarding information sharing) in the event of incapacity; however, it might also lead to residents confusing the two types of "advance directive." Conversely, a less specific name such as *disclosure of information form* might leave residents unclear about the form's purpose. Here, for purposes of clarity, the form will be referred to as a *health information advance directive.*

they did not wish their hospitalization status to be shared would be finished filling out the form. Those who did wish their hospitalization status to be shared would have additional choices about how much they wanted to be shared: e.g. the name of the hospital, the severity of their condition, and/or the admitting diagnosis, as well as any information they did *not* want shared. Residents who wanted their hospitalization publicized but did not check any of these additional options would simply have their hospitalization announced with no further details. After filling out the health information advance directive, residents would have the option to revise their preferences at any time. Residents would be reminded of their health information sharing status annually and reminded that they are welcome to change their status then if their preferences have changed; residents could also ask to change their status at any other time as well. If residents chose not to fill out the advance directive form, it would be assumed that they did not want hospitalization information shared. Importantly, a policy of requesting people's health information sharing preferences and acting in accordance with them might also be applicable to broader situations as well, particularly situations in which individuals going through health challenges together (much like AL) may form close relationships. One such situation—cancer patients going through daily radiation treatments at the same facility—is described in Nina Riggs' The Bright Hour: "You see the same people every day and then suddenly you stop seeing them. You never know if they finished treatment or if it was something else. We ask around after each other but no one ever knows for sure. 'Sorry—HIPAA,' the techs say" (Riggs, 2017). As indicated here, people in other contexts also could benefit from greater latitude in how their health information is shared, and this principle could thus be applied to a variety of contexts.

Within the context of AL, each community instituting a health information advance directive could customize it to meet their needs; for example, other instances of health information (e.g. residents moving permanently to nursing homes or to other locations) might also come up as sources of frustration or anxiety for residents, and some ALs might accordingly decide to include questions about these categories of information in their health information advance directives. Residents might also be given the option to provide a contact address or phone number for get-well cards or other communications in the event of hospitalization or a move to another location. Additionally, ALs would need to determine the specifics of how to disseminate health information at times when it became available (e.g. following the hospitalization of a resident who wanted this information publicized). An unobtrusive and easily accessible strategy might be to establish a "Get Well Soon" bulletin board in a central location, on which resident hospitalizations could be announced. Providing pens, cards, or other supplies near this bulletin board could also combine the announcement with an easy way for residents to pass on well-wishes to the hospitalized community member. Alternatively, if an AL already had a bulletin board on which other announcements were made, this could be modified to include hospitalization announcements as well.

Interestingly, a similar strategy—using bulletin boards to announce hospitalizations—has previously been proposed in industry gray literature (Finnegan, 2013). In this earlier proposal, however, the bulletin board was suggested as a resident-driven way to announce hospitalizations without triggering HIPAA-related objections. Resident family members could come to the AL and post hospitalization announcements in a public place; since these announcements were made by family members and not AL employees, they would not violate HIPAA. However, this proposition is complex to execute (and not always feasible, since not all residents have family members willing or able to take on this task), and does not address the fundamental ethical issue of conflict between resident wishes and AL staff perceptions of "care." By contrast, a health information advance directive, which would involve information sharing with the explicit involvement and assistance of the AL staff, would be easier to enact and would carry the added weight of a policy not just condoned but facilitated by the AL administration. More broadly, allowing residents to record their personal preferences regarding information sharing would reinforce their status as individuals, rather than Noddings' interchangeable "types," since all residents who completed the form would be aware that the way their health information was or was not shared represented their wishes rather than institutional policy.

Additional Privacy Training for AL Staff and Residents

Our data show the powerful bonds between residents and staff, but also reveal the ways in which these relationships can fall short. AL staff feel bound by HIPAA not to share resident health information, causing pain for both the resident and the staff member. At the same time, some staff members, wanting to accede to residents' wish for information, sometimes push (or, occasionally, violate) the boundaries of what they can legally say. The ultimate result is an AL climate in which staff members can be torn between their loyalty to residents and their concern about upholding rules (and preserving their jobs). Each staff member will respond to these conflicting forces differently, meaning that residents cannot expect any consistent policy with regard to information sharing, since health information is conveyed by unofficial "breaches" rather than institutionally established protocols. There is also lack of clarity on exactly what the privacy rules are in AL.

If AL communities establish a health information advance directive, they will make it easier for residents to share valuable health information with one another according to a predictable and consistent formula. However, such a policy will be of limited use if AL staff are not concurrently trained in its correct application—as well as the larger context of HIPAA's purpose and limitations. This training would need to establish that HIPAA's Privacy Rule does not to be (and, indeed, should not be) enforced contrary to a resident's wishes; thus, any resident who wishes to "opt out" of HIPAA for the purposes of sharing news of hospitalization with peers should be permitted to do so.

(Some staff members or administrators may be concerned about liability issues in this context. Accordingly, residents should be cautioned that health information cannot be shared unless the resident has documented this preference with a health information advance directive; upholding verbal requests may understandably be seen as an excessive legal risk to AL staff.) Reinforcing this point would ensure that health information sharing would not take place as a policy "in name only," but would instead represent an institutional commitment to facilitating resident preferences in AL.

In addition to training about HIPAA's use and limitations, staff working in ALs that offer health information sharing advance directives would likely also require a reference document indicating the privacy preferences of each resident. Communities like Parkside can have over 100 residents; staff members easily might forget which residents preferred information sharing and which residents preferred privacy. Consequently, reference sheets listing the information sharing status of each resident might be disseminated to staff members or posted in locations easily accessible to staff (e.g. break rooms, medication rooms), while also benefiting residents, who would know in advance which peers they could ask staff about in the event of hospitalization. Posting this information in a public place (where it would be visible to residents as well) might ensure further accountability from staff, but could also risk stigmatizing some residents (e.g. residents who chose not to share their information might be seen as secretive or as less-good community members). Regardless of the method used to help staff remember residents' information sharing status, staff would require training on the importance of remaining up-to-date and informed on each resident's health information sharing advance directive.

Providing training in HIPAA for AL staff would also provide another benefit: if staff members have a more complete understanding of HIPAA's boundaries—not only the information that it protects, but the information that it does *not* protect—they may be less likely to use HIPAA as a justification for lack of transparency or avoidance of uncomfortable topics. We observed several occasions on which Parkside staff members invoked HIPAA as a way of avoiding conversation about resident care issues or potential lapses on the part of AL staff. Invoking HIPAA (or referencing more generic "privacy violations," as we saw at Parkside) may seem like a valid way to preclude uncomfortable dialogue with residents and family members seeking accountability for lapses in care. Informing staff members that HIPAA does not actually cover some of the circumstances that they claimed it does (e.g. a situation when a resident's call bell was not answered promptly) may make staff members less likely to use HIPAA as a conversation-stopping strategy.

In the same vein, providing residents with basic information about HIPAA could also prove valuable. Residents who understand HIPAA's boundaries may feel less frustrated about situations in which health information cannot be shared if they have a better grasp of why this law exists and what circumstances it does and does not apply to. Furthermore, informed residents will be less likely to accept invocation of HIPAA in conditions when it does not apply, and will feel more empowered to voice valid complaints. Ultimately, a better understanding of HIPAA on the part of both residents and staff may help lead to a climate of greater transparency for the AL community.

Conclusion

By definition, AL residents are aging and declining, and many are approaching end of life. AL communities are generally legally required to abide by HIPAA, but in doing so they also contribute to an environment that does not allow resident choice and thus hinders resident maintenance of self, and makes it harder for residents to engage with issues of illness, death, and decline, which may be important for residents to discuss. In order to help facilitate maintenance of self at this life stage, it would behoove ALs like Parkside to take steps to allow residents greater choice in how their health information is shared. Our data point to problems created by a system that restricts information sharing, but also offer cause for optimism. Residents often feel close enough to one another to confide their health challenges and bond over shared circumstances, and many feel close enough with staff members to seek compromises on health information sharing. Positive relationships like these can serve as a foundation of good faith upon which new regulatory options can be introduced.

Eva Kittay writes, “An ethic reflecting concern for dependents and those who care for them demands, first, a sense of attachment to others; second, an empathetic attention to their needs; and third, a responsiveness to the needs of another” (Kittay, 1999, p. 101). Our data indicate that at Parkside, the first of these two needs are, in many cases, already met: residents and staff have interconnected and meaningful relationships despite the conflicts sometimes necessitated by their respective roles, and staff frequently demonstrated their empathy for residents’ challenges. Yet the third component, responsiveness to the needs of another, still must be remedied, at least in regards to health information sharing. Residents’ need for health information reflects their concern for their peers, their wish for respectful and open treatment, and their recognition of their life stage. Through recognizing this need and responding to it, AL can fully adopt an ethic of care that benefits all community members.

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