

Beyond impediments to caring

Toward a morality of late-life care

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A primary caregiver's responsibility to arrange late-life care can be challenging in light of the various obstacles confronted in different kinds of care settings and care giving arrangements. Using examples from nursing home care, a foster home, and home care, this article describes particular constraints imposed on formal caregivers that compromise their imperative to care. Drawing from observations of caregivers who circumvented these obstacles and from the dialogical ethics of Buber and Levinas, the article briefly considers the requirements for a morality of late life caregiving.

[end-of-life care, morality of care, care ethics, dementia care, nursing homes, foster homes, home care]

Orchestrating late-life care (end-of-life care and/or long term dementia care)¹ for a family member or loved one can be emotionally wrenching for the person who assumes responsibility for care² as the 'primary caregiver'. Primary caregivers strive to make the best decisions for their ailing relative while working within a mélange of delimited care offerings.³ Their course of action and the care they seek, however, may be compromised by competing pressures from service providers (homes, agencies or others who arrange for the provision of formal care), operating under their own professional, institutional and economic constraints.

Primary caregivers must navigate among a large array of care options to select those most suitable to the changing needs of their elder while fulfilling the moral responsibility to provide care. For adult children this derives from an intergenerational reciprocity, or implicit 'contract between generations' (Bengston & Murray 1993: 112), based on resource exchange (Graham & Bassett 2006: 336) and rational decision-making (Beauchamp 2001: 59-50).⁴ But a lifetime of relationship, shared history and intimacy introduces a personal, emotional dimension to the care seeking process that extends beyond the bounds of rationality or contract. Based on that history and personal circumstances, filial reciprocity for some will end once professional care is secured. The great majority of primary caregivers, however, remain engaged in their

relative's care even after formal arrangements have been made (Bowers 1988). These caregivers are likely to seek the kind of care they themselves might wish to render: *personalized* engaged care, respectful of the elder's biography and supportive of the person; care that *is attentive* and responsive to the elder's needs and wishes; and care that is a *good fit* between the elder and caregiver. Such care, sometimes called 'person-centered' or 'relational,' depends on an enduring, often loving (cf. Trakas 2008), relationship between caregiver and receiver, one nurtured by the intimacy demanded by the very act of care giving. 'Person-centered' care contrasts sharply with standardized task-centered (or 'instrumental') care, driven instead by the care priorities of the provider or facility. In the United States, consumer preferences and evidence of better outcomes associated with person-centered care (Kitwood 1997; McLean 2007a) have led care providers and facilities to promote it, sometimes even using it as a marketing tool. However, securing such quality care may be difficult in a care economy dominated by the principles of rationality, control, efficiency and profit, and by reciprocal relations defined by contract, formality and instrumental values.

This paper explores various obstacles to securing quality late-life care by drawing on our combined experiences as primary caregivers and anthropologists, and on McLean's research in institutional care giving. McLean spent two years studying dementia care in two special care units⁵ of a U.S. nursing home (2007a). Several months into her nursing home study, her mother showed signs of dementia and halfway into her fieldwork, entered a nursing home. Her firsthand observation in the nursing home she studied was mutually informed by her experience as a primary caregiver (McLean 2007b).⁶ Trakas spent a summer in the United States coordinating end-of-life care for her parents, each of whom died within one month of the other (See Trakas 2008 & 2009). Her observations and experiences during that time also inform this paper.⁷

We focus on three common sites of late-life care – a nursing home, a foster home, and the person's own home – and describe the kinds of constraints each may impose on its formal caregivers (those who directly provide, coordinate or supervise hands-on care) and on other health care professionals who may be involved in an elder's care. Whether the product of institutional or contractual barriers, professional hierarchies, or ideological views about adequate care, they compromise the capacity of both primary and formal caregivers to serve the elder. However, in spite of such constraints, we observed caregivers at each site who managed to rise to the occasion and circumvent obstacles in order to exercise their moral imperative to care. Drawing on the relational philosophy and communication ethics of Martin Buber and Emmanuel Levinas, we conclude by briefly speculating on the implications of this imperative to care for developing a morality of late-life care.

Pathways to late-life care

For those with late onset dementia the course of decline, symptomatology and need for supportive care is extremely variable and uncertain. Some people are able to re-

main at home for their entire lives. Others may move to institutional care quite early on in their course. The deciding factor is often the inability of family to handle behavioral changes (confusion, agitation, wandering) that might result in injury to the elder or others. Institutionalization (nursing home care) is usually the final resort, after other community options have been tried.

In the case of end-of-life care, the journey often begins with hospitalizations that initiate the primary caregiver's involvement in arranging the care of an ailing relative. In many parts of the world, hospitals provide medical and technical monitoring but not practical care; thus, family members become the only caregivers for their hospitalized relative. The administration of medications, surveillance of vital signs and drawing blood fall into the arena of medical care and are provided by nursing staff, but actual hands-on care (e.g., feeding, toileting, washing, positioning) must be provided by family members. In contrast, in the United States, as in fully staffed 'private' or university teaching hospitals elsewhere in the post-industrial world, the hospital policy usually relegates family members to marginal caregivers whose time in the ward is limited to 'visiting hours'. Similarly, for elders residing in nursing homes, families may be seen as marginal, or even as an intrusion to their care (Foner 1995). In fact, a family may be forbidden from giving hands-on care in these settings, and in some instances from even visiting (cf. Basler 2004). At the special care units McLean studied, for example, family members who had hoped to be involved in feeding their relative during mealtimes were banned from doing so because of liability concerns (e.g., injuries resulting from falls resulting from spilled food or drink).

Following hospitalization, elders may be sent to their own home with arrangements for additional nursing care at home, to an assisted living facility or smaller foster care home with nursing supervision, or to an intensive care unit of a nursing home. From there, they may eventually return home or be transferred to a residential unit within the nursing home or to another facility.

The Nursing Homes: Institutional barriers to person-centered care

As a long-stay solution, the nursing home is the most restrictive and least preferred, and generally the option of last resort. The organization of care in most nursing homes is fashioned after that of hospitals, with emphasis on regularity and control.⁸ The need to efficiently attend to large numbers of residents (often 40-60/unit) encourages routinized practices akin to hospital rounds. Although efficient, such practices are ill suited to residential living conditions and to responding to the ongoing individual needs and requests of residents and their families. Nurses trained in hospital-based acute care would be more inclined to follow this approach than those with a background in chronic care. In nursing homes, as in hospitals, the staff are preoccupied with carrying out their 'rounds' under an institutional time frame (Henderson 1995; McLean 2007c): waking up patients according to schedule, completing toileting and hygienic tasks by the time meals arrive, and overseeing medications and body care – Gubrium's classic 'bed and body work' (1997). Each unit is managed by a head nurse,

but most of the hands-on care is given by the nursing assistants (or nursing aides), as dictated by the head nurse to satisfy institutionally defined care needs.

A nursing assistant's efforts to respond to a resident's or family member's requests can be facilitated or blocked by the institution's directives. These directives emphasize management and control, and completing the task, even if the person objects. Thus, whether focused on cost containment, regulatory concerns, or administrative/ professional protocol, they prioritize the needs of the institution over the person, often to the elder's detriment. However, they also can be tempered by the degree of rigidity by which the head nurse interprets them, based on her own training and philosophy of care. These shape the care priorities she establishes for her staff.

Fulfilling institutional directives

Prioritizing efficiency over personhood

In the two dementia units where McLean conducted ethnographic research (S 1 and S 2), Dolores,⁹ the S1 head nurse, displayed an overriding concern with efficiency, which led her to reject out-of-the-ordinary requests from residents or their families. For example, one resident on the unit would become upset during her baths if water entered her ears. When her niece brought in a rubber bonnet as a possible solution to the problem, Dolores refused to try it because she felt it would impede the part-time bathing assistant, contracted to give baths, from getting all her work done. The bathing assistant would need to take the time to locate the bonnet and put it on the resident; that would cut into her allotted time to do all her baths. The facility would then have to pay her overtime – something Dolores tried to avoid. Her contractual reciprocity with the nursing home, with its efficiency priorities, overrode any contractual obligation she felt to families requesting special care. The discomfort of the elder did not even factor in to her decision. Her priorities resulted in intensified agitation in the elder, leading to several medication adjustments and the elder's precipitous decline (McLean 2007a: 113-123). With her strong medicalized view of dementia, Dolores believed the decline was inevitable. She maintained her position that the family member's request was 'unrealistic' since the elder's unremitting disease would have led to the same outcome even if they had tried using the bonnet.

The human costs of high turnover and inconsistent staff

Concerns about profit by the larger corporate nursing homes chains in the U.S. have led to cost saving measures such as staff reductions and overburdening of staff; this policy has intensified staff burnout and turnover in recent years. Increasingly, many nursing homes have thus come to rely on temporary staff, which offers the added advantage of costing less. This trend, however, has resulted in a lack of continuity of care. Temporary staff are less familiar with the resident's history, unique care needs and optimal care strategies that have been developed to assist or soothe them.

In some cases, as with McLean's mother, who resided in a dementia unit, this can have disastrous consequences (McLean 2007c). Her mother would sometimes become confused and agitated at night. The regular nurse and McLean had worked

out a procedure to avoid medication and its side effects: the nurse would immediately contact McLean to come in to calm her mother, no matter how late the hour; her presence served to comfort the elder almost immediately. The procedure was clearly noted on her mother's medical chart, and worked consistently well.

A temporary nurse assumed responsibility for McLean's mother's unit one night. When her mother became agitated, the nurse failed to read the medical chart and instead called the physician. He ordered an injection of a quick-acting anti-anxiety medication, followed by a second injection, should the first prove ineffective within 30 minutes. The trauma caused by the first injection exacerbated her mother's agitation, necessitating the second one, and left the small woman extremely unbalanced and overly sedated. The following day McLean was distraught to find her mother uncharacteristically restrained and unable to recognize her. Her mother never quite recovered from that event, having lost trust in nursing assistants who had forcibly restrained her and given her the painful shots. The facility's concerns with maximizing profit over care led to control tactics that proved disastrous to McLean's mother.

Prioritizing the standards over the person

The institution where McLean was conducting research was making efforts to comply with national standards to reduce the level of restraints used in the facility. A resident of the S1 unit had been restrained in a geri chair (a chair on wheels with a tray on top serving as a restraining device). He hated being in the chair and broke it in his effort to escape from it. The man was more content when placed in a harness tied to a chair, even though the harness was regarded by national standards as a more restrictive restraint than the geri chair. In an effort to comply with the institution's directive to use less restrictive restraints, the S1 head nurse insisted that the man return to his geri chair after it was repaired, even though he accepted an alternative. By giving precedence to the objective standard over the elder's subjective response, the nurse ironically defeated the very purpose of the national standards to improve the lives of residents.

Extending instrumental control over primary caregivers and families

A nursing home can extend its institutional control not only over residents, but also over primary caregivers and other family members through the exercise of court authority. In McLean's mother's facility, before she and the head nurse had developed a procedure to handle her mother's nighttime agitation, an administrator threatened to have her mother court committed to a psychiatric facility should McLean refuse to authorize the use of psychotropic medications to restrain her. Similarly, a Wisconsin nursing home successfully issued a temporary restraining order on a couple after they repeatedly complained about the care of their two mothers who resided there (Basler 2004). The court order prevented them from visiting their mothers without giving the home prior notice. The daughter was not even allowed to remain with her mother during dressing, bathing or feeding, despite the elder's emotional appeals to the staff to allow her daughter to remain.

Thus nursing homes promote standard routine care that may be deleterious for some of their residents. Since they also exercise inordinate control over the lives of

elders and their families, they can make it difficult for primary caregivers to negotiate more acceptable options to the instrumental, task-centered care they train their staff to deliver.

Setting the parameters: The head nurse's power to temper institutional directives

Each head nurse of the two units McLean studied set the tone of care giving through her philosophy of care and the care priorities she established. How she did so depended on nursing principles she had acquired from her training, her willingness to be flexible, and also her confidence in looking beyond institutional directives when this seemed necessary. Nursing assistants were evaluated by their adherence to the priorities the head nurse set; in a hierarchal and punitive nursing structure, not doing so could cost them their job.

Dolores, the head nurse from the first unit, set and rigidly adhered to her program of prioritized care routines. She refused, for example, to alter one resident's bathing schedule to accommodate another resident's needs; to do so in her view would constitute favoritism, poor nursing practice, and a violation of her contract with the nursing home to conduct quality nursing. Her nursing assistants were obligated to follow her rigid directives, prioritizing meals over toileting (even in an emergency: "that's what diapers are for"), instrumental care tasks over residents' requests for company or attention, efficiency over relationship. While sincerely executing the principles of good nursing by which she was trained, her dictates created challenges for those nursing assistants who wanted to take the time to interpersonally engage with residents as they conducted their care routines; involving the elder, they had learned, made the task go faster, was more enjoyable, and produced less resistance from the elder. Dolores, however, castigated Charles (whom families adored) as 'lazy' for taking the time to chat with a resident during the daily rounds, while praising Dawn (whom families dreaded) for efficiently completing her tasks.

Jane, the head nurse of S2, the 2nd unit, had opposite opinions of Charles and Dawn, and was even surprised that Dawn had not yet been dismissed for her rough handling of residents. In contrast to Dolores, Jane encouraged her staff to attend to individual needs and preferences as much as was possible, given the other pressures that they faced. She did this by exercising uncommon flexibility in organizing care. She would sometimes suggest, for example, postponing a medical appointment of a resident having a 'bad day' until he/she felt better. On other occasions, she would recommend interchanging two residents' bath schedules to accommodate one of the resident's plans to join a family outing scheduled during her/his bath time. She did so to support both the elder and the family. Jane would invite primary care givers to meetings to discuss their elder's care plan – even though it might slow the meeting down. She kept in regular contact with the family and served as the unit social worker to be aware of family issues and better serve the elder. Jane's extensive background in long term nursing care may have predisposed her to appreciate the value of such person-centered approaches; still, she was exceptional among other head nurses from similar backgrounds at the 500-bed facility. In private conversations with McLean, Jane spoke

empathetically of the suffering of primary caregivers who were witnessing their parents' slow decline. McLean suspected that her ability to empathetically engage with this suffering was responsible for her dedication as a nurse, and her imperative to care.

Nevertheless, even in Jane's more flexible unit, nursing assistants could not avoid pressures to complete repetitive rounds of care tasks, mandated by state legislation, for 8-10 residents in a 7½ hour shift. The intense demands of the nursing home, with its large resident load, regulatory requirements and concerns with efficiency and control inevitably favored an environment that encouraged instrumental care over responsiveness to persons. Still, there were those, like Jane, who continued to find ways to relocate the person at the center of care.

The Foster Care Home: Supporting diverse ways of attentive caring

When the primary caregiver and the other family members are dissatisfied with the extreme restrictions or the institutional character of most nursing homes, there are other intermediate options between home and institution. These will vary with the needs of the elder, the family's finances and, state and federal government policies that may favor some options as more affordable. The options – independent living (which provides the least amount of assistance), and assisted living (including small foster care homes, sometimes called 'board and care') – vary in service offerings, degrees of hominess and medicalization, and cost. (See note 2 for more elaboration on options and cost.) The smaller foster homes provide the strongest semblance to a family home given their informal operations and casual atmosphere (Eckert & Morgan 2001) that permit familiarity of the small, but stable, staff with both residents and their families. Some foster homes are family operations for which elder care was assumed as a mission, passed on over generations, and devoted to flexibly satisfying the comfort needs of elders and their families. Other foster homes operate more strictly as businesses, permitting flexibility only if cost containment is not risked.

Although foster care is not regulated in all states, foster homes are typically staffed by 'health care aides' who have undergone the same training and certification as those staffing nursing homes. Some of the aides have been entrenched family caregivers, that is, people whose identities as caregivers derive from their history caring for members of their own family. For these women, caring is simply what one does when it is needed; there is no choice in the matter (cf. Rosenberg 2003). They view care giving as a continuous fluid process, rather than a fragmented set of isolated tasks. Some of these care workers opted out of more regimented nursing homes or rehabilitation units to seek a less formal, instrumental orientation to care. Still others are registered nursing or medical school students, seeking additional contact hours with those in need. Foster care aims to provide 'homey' and safe low-cost care by allowing the purchase of additional services only as needed – an RN to dispense medical treatment, a special night-time companion, or a special companion to take the resident out for walks or to a doctor's appointment. Such homes are also amenable to hospice ideology and collaborations with hospice professionals and volunteers.

Because of the many different types of care giving professionals who potentially may participate in late-life care at foster homes, tensions may develop between caregivers holding competing philosophies of care or different personal styles. When Trakas' father moved to a foster care home during his final weeks of life, regular clashes occurred over his care between the caregiver Trakas had employed from an outside agency and the nursing assistant on staff at the home. Shannon, from the outside agency and trained in hospice care, saw no reason to dispense medication the elder could not swallow, but Peggy, the foster home aide, insisted on placing the pill under his tongue, where it would dissolve and be absorbed. And when Peggy honored the elder's requests to remove all clothing for reasons of comfort, Shannon accused her of neglecting to keep the man warm. Such clashes reflected differences not only in their training perspectives (hospice versus more interventionist medical) and related care biases, but also revealed their perceptions of moral responsibility to the person under their care, as well as their emotional attachment to him. In addition, the foster home caregivers were aware that Shannon, along with others trained in hospice care had previously taken care of him and his wife in their own home. This created an implicit competition and desire for control and personal favor by both the elder and family. In this case, the conflicts occurred not between the primary and other caregivers, but between the formal caregivers themselves, whose competition worked to serve the elder well.

In contrast to the nursing home, which constrained the ways in which caregivers could care, the small more intimate casual setting of this foster home permitted different styles of caring, even to the point of contention. The setting afforded them the privilege to express their imperative to care as they envisioned it from their training and inclination to serve. As an assisted living option, this foster home assisted not only her father, but also Trakas, who was facing a very difficult time.

Home Care: Contractual contradictions against securing a good fit

When the home becomes the locus of end-of-life care, even for a short period, the provisioning and consumption of technical care in a space historically dedicated to informal family living may disrupt the workings of the household, alter familial relationships (Wiles 2005: 83), and violate its sentimental and biographical meanings for family members. The positive associations of 'home' with warmth, comfort, and freedom (Williams 2002: 147) nonetheless make it the place in which most people would prefer not only to live, but also to die (Brent 1999: 70; Peace et al. 2006: 47). Many elders expect that they will retain their dignity when receiving care in their own terrain rather than in some anonymous setting where they are seen as just another stranger among strangers. The home becomes a contested site for care, however, when it is the locus of care giving, because there is a collapse of public and private space (Milligan 2000: 55), creating ambiguity and potential tension between household members and the formal caregivers who provide care there. In recognizing and attempting to avert potential conflict, home health care agencies advertise their efforts to identify home

aides who will be a good 'fit' with the family, presumably taking into account the family's socio-economic and cultural profile, the elder's needs, and judgments about personality compatibilities.

Consistent with names such as 'Empathic Caring', 'Family Compassion', and 'Home Hearth', in-home care agencies advertise flexibility of staff, control by the elder clients and continuity in care by claiming to provide consistency in the home aides they assign to each household. The financial priorities of the business and the agency's own policies, however, may in fact serve to undermine these goals. Agencies, for example, follow a 'no friendship' policy designated in the care contract. The clause warns that the client must not make personal arrangements regarding services and scheduling directly with the aides (Trakas 2008: 126-7). Some contracts forbid individual arrangements with the aides for up to a year after care has been terminated, a tactic designed to prevent aides from resigning from the agency to pick up work on a private pay basis with a special client. The strategy is intended to protect the agency from losing their minimal-wage workers who typically receive only 40% of the agency's \$20+ hourly wage. These contractual conditions are intended to protect the agency; if the fit is too good, aides may find themselves as recipients of non-monetary gifts from their elderly charges or an appreciative family member. Aides may then innocently offer extra time or complimentary services, like driving a client to the doctor – acts seen as economic threats by the agency. Thus contractual reciprocity is conditioned by economic concerns, which may well elude the relationships that develop between caregiver and receiver. These concerns nonetheless contradict the purported promise of securing a 'good fit' between caregiver and family.

Physicians who altruistically follow-up on their patients' care are praised for their humanitarianism, as this is seen as being over and above their charge (Kleinman & Van der Geest 2009: 161); home care aides who offer an extra hour of service out of concern or affection for their client are reprimanded, or even fired. The development of friendship reciprocities threatens the formal contractual relationship, which conceptualizes care as a detached deliverable service which the agency controls. Agency home aides are continually caught in the middle between their employer's expectations of acceptable care giving and their own. Indeed, aides may try to evade the agency's demands in order to improve their economic situation by reaping a fuller reward from their labors. For others, however, external care giving beyond contractual arrangements may signify something deeper – a moral or even spiritual act or commitment. Trakas encountered both extremes when coordinating home care for her parents, but several of the aides voluntarily gave 'off the record' time out of their sheer pleasure of being with the elders. They would bring small gifts and readily render care as needed during their own 'free' hours. Any suggestion of payment or reward was rejected as somehow tainting the balanced specialness of the relationship and genuine emotional bonds that had developed between her parents and the caregivers.

This element of friendship and human connection puts a snag in the economic agenda of the for-profit home care agencies. Aside from clauses in the contract, home care agencies have more informal ways of handling outbreaks of emotional reciprocity, friendship and moral responsibility in their workers. Their service coordinators

become highly attuned to evidence of developing bonds between a family and aide (economic threats to the agency), and may deliberately ignore the family's requests for a specific aide. As a precaution and strategy to overcompensate for such threats, agencies may regularly change assigned workers (contradicting their claims of consistency), query suspected independent arrangements, or challenge requests for changes in services. For example, as soon as Trakas voiced preference for a specific aide, the coordinator began to assign her to another home! The frequency of this occurrence suggested it was not a random event. To Trakas' surprise – and contrary to the agency's rhetoric and contract – the coordinator even admitted to making assignments that would not succeed! Even more disturbing, the coordinator appealed to Trakas' moral and filial responsibility to trust her judgment, as an experienced health care professional, in determining assignments, thereby confounding business, professional, and personal ethics. Although the coordinator may represent an extreme case, this example renders transparent the economic considerations that may inadvertently shape less optimal assignments of aides by other home agencies as well.

Agencies schedule and provide care, and elderly clients or their families pay a fee-for-service; this constitutes contractual reciprocity. Even though the contractual arrangement may be responsible for introducing a home aide into a formal care giving arrangement, once a reciprocal relationship develops with the elder, it is often cherished by both elder and caregiver, and not easily dissolved or successfully blocked by the agency's will or machinations. Trakas found several of her parents' aides devoting tireless energy to playing games, singing and cajoling her parents to join in, wearing funny hats for their amusement, or sharing countless hours just sitting in the sunshine patiently listening to stories of days gone-by. These are the priceless side activities, beyond contracted 'services,' which fill the endless space of aging and caretaking and emotionally sustain both elder and aide. Such 'in the moment' emotional reciprocity, however fleeting, threatens the formal contractual reciprocity of home care agencies, inadvertently defying their demands for economic safeguards.

However satisfying these spontaneous and reciprocal 'feel-good' moments may be – and however they may challenge the profit-driven agendas of the agencies – there is yet a greater threat to contractual care. This threat lurks in the more mundane rendering of such contracted 'services' as feeding, grooming, toileting, pill dispensing. It is here where 'service' may be transformed to genuine 'care' (cf. McLean 2006: 6-7; McKnight 1995: x), dramatically transforming obligatory contractual reciprocity to a moral reciprocity and imperative to care based on relationship and love.

Discussion

Each of the above sites produced its own particular constraints and barriers to late-life care, but by no means dictated the possibilities that could occur there; indeed at every site there were caregivers who managed to circumvent these obstacles. Every setting created particular challenges for the care giving staff to fulfill obligations for contracted services. Moral beings though are not defined strictly by the rational be-

haviours contractual agreements presume. Institutional constraints, filial obligations and personal relationships with formal caregivers confound the expectations of contractual reciprocity in contra-distinction with moral responsibility. The imperative to care of the caregivers we observed was not confined within restrictive contractual reciprocities; indeed the most compelling reciprocities occurred within caring care giving relationships. Though not apparent in all caregivers, this impulse to care transcended the boundaries of locus and contract.

Philosopher Charles Taylor (1991) argues that Western society must recover its lost cultural identity to embrace all generations within a broad shared cultural and spiritual tradition. He argues that such a tradition could link elders with caregivers, even when they lack knowledge of an elder's particular history, adding that this shared identity could serve to overcome the strong disconnect between caregivers and receivers. The empathic caring of the exceptional caregivers we encountered in research and experience as primary caregivers is evidence that Taylor's aspiration is within reach.

Toward a morality of late-life care giving

Instrumental care giving, directed at contractually completing prescribed care tasks, ignores the subjectivity and appeals of the person receiving care; even worse, it denies her personhood, as it *uses* her as the very *means* by which the caregiver completes her/his tasks. Such is the epitome of the dehumanizing 'I-it' relation (Buber 1996) – one of power wherein the person is simply 'processed' by the caregiver (McLean 2007a: 184). These instrumentally defined relations offer no space for suffering; indeed expressions of suffering are seen to interfere with the completion of the task!

In sharp contrast, Sally Gadow locates empathic care giving in 'mutuality' (1985: 40-41), through an awareness of mutual vulnerability to suffering. It is this awareness that reduces the distance between caregiver and receiver. Further, Gadow notes, that touch is the vehicle that reveals this vulnerability. Significantly, when touch is empathetic, and sensitive to human suffering, the 'I-it' relation is transformed to one of 'I-thou' acknowledgment and respect (Buber 1996). Indeed Martin Buber's reciprocal ethics, fundamental to the dialogic care giving/ receiving relation, is rooted in mutuality; only through mutual participation of both members can the higher 'thou' be attained (Wallace 2001: 217).

Among the finest caregivers McLean had the privilege to witness was Elaine, a nursing assistant at the S2 unit. For her, care giving was a spiritual practice that embodied an ethic of intimacy and love, meaningful in itself in spite of the lack of expectation of cure (cf. Gadow 1988). Through gentle persistence, she engaged intersubjectively with each elder, working together to nurture both body and spirit as she drew out the person who remained. With cure out of the question, she aimed to preserve the elder's dignity and minimize vulnerability, without losing herself in the process. Her reward for such reciprocity was the powerful sense of belonging to something greater than herself.

Yet there may come a point when reciprocity is no longer within the realm of apparent possibility. McLean's research with exceptional caregivers like Elaine has led her to question the very necessity of reciprocity as a fundamental feature of care.

When a person with dementia can no longer clearly respond to the caregiver, how can the relationship remain reciprocal? In such cases, Martin Buber's reciprocal dialogical 'I-thou' ethics, which imply mutual participation, may reach a limit point as the elder withdraws into profound interiority. It is here where the reciprocal, horizontal ethics of Buber (Wallace 2001) may yield to the possibly more elusive, asymmetrical ethics of Emmanuel Levinas. Levinasian ethics obligate the caregiver to respect the rights of the 'radically other' out of sheer 'respect for the face' (Marquez 1987) – a divine moral calling, which selflessly draws in the caregiver, securing an arguably even higher, transcendent reciprocity (cf. McLean 2007d). Indeed for Levinas, the intersubjective relation is at its most ethical when reciprocity is *not* possible, because elevation of the other results purely out of a respect that inspires non-egoistic moral responsibility without any consideration of gain (Marquez 1987: 345-6). The only demand upon the caregiver is to be present to listen (Lipari 2004: 137) and "to respond with responsibility: *me*, that is, *here*, *I am for the others*" (Levinas 1998: 185, cited in Lipari 2004: 130).

Conclusion

The challenges of late-life care giving are amplified by competing understandings of the nature of care and how care giving should be organized, administered, and ultimately rendered. How formal caregivers interpret their charge within the constraints of the various settings in which they render care shapes the practice ethic each adopts, along a continuum from instrumental service delivery to empathetic care work. The consequences of their choices are immense for all whom they touch, and yet they are not totally free to act alone, undoubtedly constrained by the demands of their setting. Surely constraints can exist in all settings, but the rigid boundaries of institutions and their instrumental mindsets make them special challenges for empathetic care work. Yet even in the intimate setting of home, care work can be constrained by contracts designed to ensure profits over person sustaining care.

As described within this article, however, such challenges may be countered by the genuine human impulse to care. Such an impulse defies the confines of rational contract through its 'free' and unself-conscious offering of care. Trakas' parents' caregivers, as examples, offered their company to her parents out of sheer enjoyment and a longing to be with them. Within these caregivers' own terms, caring could be neither contained nor measured; it was bound neither by time nor cost. More profoundly, it was necessitated by 'the face' of the elder – a beckoning for reciprocal engagement out of sheer love and a Buberian practice ethic.

Boundless impulses by caregivers such as these trouble the limitations imposed by rationalized, instrumental economies of care. As naturalistic, ethical actions, these impulses to care are hard to realize within economically motivated structures defined in terms of procedure, time, and dollars, beyond the realm of true suffering and subjective need. And yet we find the care giving enterprise dominated by a rationalized, economic, model of care giving, embedded in what Moody calls the, potentially

treacherous, instrumental reasoning behind scientific gerontology (1988). As social scientists, our challenge is to encourage societal movement against this trend, and toward an alternative ethic of care practice attentive to the voice, personhood, and suffering of the other. This may derive from Buber's appreciation of our mutual vulnerability and humility over the fragility of the human condition – invoking Taylor's new 'horizon of meaning' (1988) – or from Levinas' ethic that honors radical difference.

Needless to say, this challenge is daunting in a society dominated by policy makers tied to rationalized cost-saving models that serve neither caregivers nor elders and their loved ones; it is particularly daunting in the United States, where the care industry is driven largely by the profit motive. Western society is in a crisis given the ruptured capacity of its members to fulfill their filial obligations to care for their own in the absence of adequate social and economic supports. As an aging society we are further challenged by an inadequate number of available caregivers, and the startling devaluation of their economic and social worth. This has given rise to their high turnover, something we can ill afford. And yet there are still exceptional caregivers who defy adverse conditions to extend themselves fully in sustaining those under their care. We must find ways to nurture such carers, and encourage others who may have been drawn to the caregiving profession out of a mission to care, but lost their way under various pressures. We need to develop a morality of late-life care to encourage and support caregivers like these. Such a morality should underline the fundamental importance of relational person-centered caring at this late stage of life and restore respect to those professionals who are motivated by the imperative to care. Building on previous works (e.g., Tronto 1993; Hankivsky 2004; and Baars 2006: 32-40), we must further encourage a system of care giving that prioritizes this imperative to care rather than demanding that it be suppressed for other, *non-caring* purposes.

In a recent interview, Canadian Archbishop Lazar Puhalo discussed society's moral obligation toward vulnerable populations. His comments can inform our thinking about a morality of late-life care giving. 'True morality,' he suggested, requires that we enter into another's suffering and try to bring the person out of it, doing so in a manner that respects the person's equal humanity (Puhalo 2010). He equated such morality with healing.

We propose that insofar as care providers (homes, agencies or other dispensors of care) and those responsible for deciding about their operations (top management and boards of directors of the facilities or agencies, but also policy makers and regulatory agencies that define standards and ensure compliance) create environments and conditions that support caregivers in this moral charge, they are advancing a morality of late-life care provision. Insofar as they nurture those caregivers who already have an imperative to care and gently provide guidance for others on how to follow their lead, they will also make great strides toward this end. Such a charge may require considerable reframing and restructuring of our late-life care delivery system, and no doubt there will be resistances from those who see late-life care in more instrumental terms. The shift will not change the provision of safety, physical maintenance and medical treatments demanded in late-life care giving, but it will insist that they be rendered in a caring manner that respects the suffering of the other. As Taylor suggested, such

a shift may first require a broader societal and spiritual transformation to revive the sense of mutual responsibility that takes us beyond our own selfish ends. Whatever it requires, a guiding morality of late-life care will soften the suffering experienced by all who participate in this inescapable chapter of the human condition.

Notes

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- 1 The 'late-life' care explored in this article includes both late onset dementia care and 'end-of-life' care. The latter is typically seen as distinct from late onset dementia care because it is often associated with the unspecified period in a person's life, before an anticipated death. Late onset dementia, in contrast, has a varied length of illness course, ranging from 3 to 20 years, where the period of expected death is less predictable. For the purposes of this article, the particular type of elder care – dementia or end-of-life – is less important than our encounters with the care systems in negotiations about the care to be given. Thus, in the article, we classify both categories of care under a common label, 'late-life care'.
- 2 Care, care giving, and caring are used throughout this paper, but not interchangeably. We intend 'care' to refer to the product or task completed in helping another with body care/maintenance, that is, the act of care giving; it can be done instrumentally (focused strictly in accomplishing the task) or in a caring manner. 'Caring' refers to the attentive, relational, sensitive, and possibly emotionally engaged manner in which care is rendered.
- 3 Navigating the world of care is a particular challenge in the United States, where care is overwhelmingly private and for-profit. The consumer must navigate a mélange of commoditized offerings, varying widely in cost and ranging from a variety of skilled and unskilled in-home services to the selection of skilled nursing services in institutionalized settings. The availability of public funding for late-life services varies from state to state, as arranged contractually with the federal government, through grants to the states. Typically, some

public funding is available for hospice care. Within long term care services, most states consistently offer funding only for nursing home care, which is federally and state regulated. These services, however, are only available under Medicaid, medical funds reserved for the indigent. Because nursing home costs are so high (typically ranging from \$5000-\$9000/month), most people who enter a home as private payers spend down their private savings to the point where they qualify for a Medicaid grant. Foster care homes (also called ‘assisted living’) are about one half the cost range of nursing homes. They may or may not be regulated, depending on the state and do not automatically qualify for Medicaid grants. Some states may provide waiver funds within the Medicaid program to allow for lesser amounts of spending for in-home care or at assisted living facilities, for those who qualify, but this differs among states and policies vary even within a given state over time.

- 4 It is notable that moral agency is a concept that draws on John Locke’s emphasis on rationality, continued in the work of many bio-ethicists today, as the basis for judicious decision making – a concept that utilizes non-moral cognitive characteristics to impute morality (see also Beauchamp 2001: 59-60).
- 5 These were the historic, Sley units (I and II) of the Philadelphia Geriatric Center – designed by environmental psychologist M. Powell Lawton.
- 6 In a chapter elsewhere (McLean 2007c), McLean explores the research and ethical challenges, as well as unique opportunities for insight, raised by the exceptional circumstances that led her to simultaneously experience as a family member the very subject – nursing home dementia care – she was researching. The challenge as a researcher, she concluded, was to remain acutely aware of the positionality of each status – researcher and family member – while also capturing unique access both to the subjective suffering of families, as well as to the ways in which they were regarded by nursing home staff.
- 7 As a co-authored paper, the subject speaking may vary in different sections of the paper. The observations and experiences of Trakas or McLean are attributed to each by name, e.g., “Trakas said” etc. At other times we use our plural voice.
- 8 Pressures to create less regimented, more homelike options, that share the same eligibility criteria, have led to more creative options that nonetheless qualify as ‘nursing homes.’ Novel designs and alternative demedicalized approaches to care, such as the Green House Project, developed by William Thomas, have created smaller 10-person homelike houses in communities, with clusters of four homes counting as a single nursing home (Kane et al. 2007). In fact the movement to transform nursing homes into more homelike environments is catching on as consumers find them more appealing. While many facilities now have a homier appearance the challenge to reorganize care giving so that it is less regimented, allows for more flexibility and can allow for greater relaxation of the caregiver requires a changed mindset that has been more difficult for administrators and staff to embrace.
- 9 For purposes of confidentiality, the people in this article are identified by pseudonyms.

References

Baars, Jan

- 2006 Beyond neomodernism, antimodernism, and postmodernism: Basic categories for contemporary critical gerontology. In: Jan Baars et al. (eds.), *Aging, globalization, and inequality: The new critical gerontology*. Amityville, NY: Baywood, pp. 17-42.

- Basler, Barbara
 2004 Battle of the banned: Couple fights court order limiting visits to nursing home. *AARP Bulletin* 45 (10): 28-29.
- Beauchamp, Tom L.
 2001 The failure of theories of personhood. In: David Thomasma, David Weisstub & Christian Hervé (eds.), *Personhood and health care*. Dordrecht: Kluwer Academic Publishers, pp. 59-69.
- Bengston, Vern & Tony M. Murray
 1993 'Justice' across generations (and cohorts): Sociological perspectives on the life course and reciprocities over time. In: Lee Cohen (ed.), *Justice across generations: What does it mean?* Washington, D.C.: American Policy Institute, AARP, pp. 111-38.
- Bowers, Barbara
 1988 Family perceptions of care in a nursing home. *The Gerontologist* 28 (3): 361-67.
- Brent, Ruth
 1999 Gerontopia: A place to grow old and die. In: Benjamin Schwartz and Ruth. Brent (eds.), *Aging, autonomy and architecture: Advances in assisted living*. Baltimore: Johns Hopkins University Press, pp. 63-80.
- Buber, Martin
 1996 *I and Thou*. New York: Touchstone [1937].
- Eckert, J. Kevin & Leslie A. Morgan
 2001 Quality in small residential care settings. In: Linda S. Noelker & Zev Harel (eds.), *Linking quality of long-term care and quality of life*. New York: Springer Publishing, pp. 3-26.
- Foner, Nancy
 1995 Relatives as trouble: Nursing home aides and patients' families. In: J. Neil Henderson & Maria Vesperi (eds.), *The culture of long-term care*. Westport, CT: Bervin & Garvey, pp. 165-78.
- Gadow, Sally
 1985 Nurse and patient: The caring relationship. In: Anne H. Bishop & John R. Scudder (eds.), *Caring, curing, coping*. Tuscaloosa, AL: University of Alabama Press, pp. 31-43.
 1988 Covenant without cure. Letting go and holding on in chronic illness. In: Jean Watson & Marilyn Anne Ray (eds.), *The ethics of care and the ethics of cure: Synthesis in chronicity*. New York: National League of Nursing, pp. 5-14.
- Graham, Janice & Raewyn Bassett
 2006 Reciprocal relations: The recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies* 20: 335-49.
- Gubrium, Jaber
 1997 *Living and dying at Murray Manor*. Charlottesville, VA: University of Virginia Press [1975].
- Hankivsky, Olena
 2004 *Social policy and the ethic of care*. Vancouver: UBC Press.
- Henderson, J. Neil
 1995 The culture of care in a nursing home: Effects of a medicalized model of long term care. In: J. Neil Henderson & Maria D. Vesperi (eds.), *The culture of long term care: Nursing home ethnography*. Westport, CN: Bergin & Garvey, pp. 37-54.

- Kane, Robert L.
 2003 Professionals with personal experience in chronic care (PPECC). *Journal of Gerontological Medical Science*. 58A: M867.
- Kane, Rosalie et al.
 2007 Resident outcomes in small-house nursing homes: A longitudinal evaluation of the initial Green House Program. *Journal of the American Geriatrics Society* 55: 832-39.
- Kitwood, Tom
 1997 *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Kleinman, Arthur & Sjaak van der Geest
 2009 'Care' in health care: Remaking the moral world of medicine. *Medische Antropologie* 21 (1): 159-68.
- Levinas, Emmanuel
 1998 *Otherwise than being*. Pittsburgh, PA: Duquesne University Press.
- Lipari, Lisbeth
 2004 Listening for the Other: Ethical implications of the Buber-Levinas encounter. *Communication Theory* 14 (2): 122-41.
- Marquez, César A. Moreno
 1987 The curvature of intersubjective space: Sociality and responsibility in the thought of Emmanuel Levinas. In: Anna-Teresa Tymieniecka (ed.), *Morality within the live and social world*. Analecta Husserliana 22. Dordrecht: Reidel Publishing, pp. 343-52.
- McKnight, John
 1995 *The careless society: Community and its counterfeits*. New York: Basic Books.
- McLean, Athena
 2006 From commodity to community in nursing homes: an impossibility? A Forum article. *Ageing & Society* 26: 925-37.
 2007a *The person in dementia: A study of nursing home care in the U.S.* Toronto: University of Toronto Press.
 2007b When the borders of research and personal life become blurred: Thorny issues in conducting dementia research. In: Athena McLean & Annette Leibing (eds.), *The shadow side of fieldwork: Exploring the borders between ethnography and life*. Malden, MA: Blackwell Publishing, pp. 262-87.
 2007c Dementia care as a moral enterprise: A call for the return to a sanctity of lived time. *Alzheimer's care today (formerly Alzheimer's Care Quarterly)* 8 (4): 360-72.
 2007d The therapeutic landscape of dementia care: Contours of intersubjective spaces for sustaining the person. In Allison Williams (ed.), *Therapeutic landscapes*. Aldershot/ Burlington, VT: Ashgate, pp. 315-32.
- Milligan, Christine
 2000 'Bearing the burden': Towards a restructured geography of caring. *Area* 32 (1): 49-58.
- Moody, Harry
 1988 Toward a critical gerontology: The contribution of the humanities to theories of aging. In: James Birren & Vern Bengston (eds.), *Emergent theories of aging*. New York: Springer Press, pp. 23-29, 36-37.
- Peace, Sheila, Caroline Holland & Leonie Kellaher
 2006 *Environment and identity in later life*. Buckingham: Open University Press.

- Puhalo, Lazar
- 2010 Orthodoxy of the heart. Spiritual talk (Meleti) of Archbishop Lazar in San Luis Obispo, CA, May 10, 2010. http://www.youtube.com/watch?v=LRpuky2_R0 (part 4/5) and <http://www.youtube.com/watch?v=5ksKBm-fstY&feature=related> (part 5/5)
- Rosenberg, Harriet
- 2003 Complaint discourse, Aging and caregiving among the Ju/'hoansi. In: Richard B. Lee (ed.), *The Dobe Ju/'hoansi*. Stamford, CN: Wadsworth/Thompson, pp. 91-108.
- Taylor, Charles
- 1991 *The ethics of authenticity*. Cambridge: Cambridge University Press.
- Trakas, Deanna
- 2008 Loving to death: Sickness in the twilight years and end-of-life care. *Medische Anthropologie* 20(1): 121-38.
- 2009 Fragile lines in care: Humour, conflict, authority in a foster home for the elderly. Unpublished paper Symposium 'Care & Health Care', Amsterdam.
- Tronto, Joan C.
- 1993 *Moral boundaries: A political argument for an ethic of care*. New York: Routledge.
- Wallace, B. Alan
- 2001 Intersubjectivity in Indo-Tibetan Buddhism. In: Evan Thompson (ed.), *Between ourselves: Second-person issues in the study of consciousness*. Thorverton: Imprint Academic, pp. 209-30.
- Wiles, Janine
- 2005 Home as a new site of provision and consumption. In: Gavin Andrews & David Phillips (eds.), *Ageing and place: Perspectives, policy, practice*. London: Routledge, pp. 79-97.
- Williams, Allison
- 2002 Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine* 55: 141-54.