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“That model is sooooo last millennium!” Residential long term care as a system, not a place

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Abstract

The current quandary with the design of existing long term care (LTC) settings results from focus on structures (“institutions”) instead of on a system of supports and services that transcends physical and traditional boundaries across settings, including nursing homes, assisted living residences and the home. Supported by analysis of the commonalities, socio-historical and political contexts, core values and fallacies of social and medical models in existing and emerging LTC options, a holistic model is proposed based on new core values which facilitate community and family integration, and which asserts dignity and personhood as universal attributes in an array of settings.

Introduction

Bella, 84, lives in a senior retirement center, with ADL and IADL support through a special program in which aides and nurses circulate to her apartment. She is stiff from arthritis and refuses to join in exercise class, or help dress and bathe herself.

Brian is 60 and a short-term visitor to the Wells Nursing Home, following a total hip replacement. His partner works full-time so a 2 week stay in the rehab program would greatly reduce the strain on her while increasing the security and rehab gains for him. On his first morning at Wells, he asks for a cup of REAL coffee. He is told that only decaffeinated coffee is made on the premises because caffeine keeps the elderly up at night. From the age of 16, Brian has started almost every morning with coffee. To top it off, he has just had major surgery, and is constipated from combined inactivity and narcotics for postoperative pain. He asks for some prunes. He is informed that a doctor’s order is required.

Maria, 90, lives with her husband of 70 years in an apartment building. Both were very active until Maria started falling without warning. She was also becoming increasingly incontinent and showing worrisome lapses in memory and judgment. Her adult children assumed that these were normal consequences of aging, and attempted to address the

problem by getting the couple to accept more personal care and supervision from hired assistants, but Maria's husband refused all help.

These vignettes will be referred to throughout this article to illustrate the ambiguities and inconsistencies in current USA long term care policy which binds needs for long term care to categories of place. With these vignettes, we untangle the events and circumstances that have shaped today's long term care environment. In conclusion, these stories are framed in alternate endings, constructed by a philosophy of long term care (LTC) as a system, not a place; a system without walls that transcends myths of aging, traditional disciplinary barriers and historical misconceptions.

Through analysis of the socio-historical context for long term care in the USA, we reveal the deleterious dichotomy of today's competition among social and medical models in emerging LTC options. Core values of both models are exposed in relation to broader social ethics, American cultural values, and the political-economic landscape across federal and state lines. Common barriers and ambiguous boundaries are exposed by comparing today's existing and emerging options and philosophies for LTC, including institutional and congregate settings, self-directed care, and home and community based programs.

It is important to examine the definition of the term "institutional" long term care. By definition and connotation, an "institution" is not a residence where people have control, but where a centralized, administrative body controls the range of options available (Goffman, 1961). Brian's story typifies this definition wherein blanket policies and practices are based on a generalization of group needs which is applied to all residents. Also, in an institution, services are highly centralized. The opposite of an "institution" is often thought of by many Americans as a "home." However, in today's LTC landscape between institutional settings that house many people and the private individual home, there is a growing array of congregate settings for the elderly, among them assisted living facilities, posed as alternatives to nursing homes. The nursing home in the USA represents the epitome of an institution, and one that has suffered a persistently bad image among Americans, as a place to be avoided, for reasons traced in this article.

To rise above the confusing and often disappointing plethora of institutional and residential options for the elderly in the USA, we propose the vision of LTC as a system, not a place. We apply principles of interdisciplinary collaboration outlined by Rosenfield (1992) to transcend common difficulties when different disciplines—and stakeholders—bring competing paradigms to the table. Barriers to enactment of the new vision are discussed, including the harsh divides between practice and research in gerontology.

We close with a new vision, outlining new core values that emphasize dignity, choice and individualized care as universal attributes of the LTC system. The reach of the new vision offers hope of more comforting futures not only for the older adults in this story, but for the families and new communities that form as a result.

In order to move forward, we begin with a glance backwards. Socio-historical contextualization will help us to understand the moments that have led us to where we are today as a nation in the provision of long term care for our population. First, we trace LTC history in the US, beginning well before the Hill-Burton Act of 1965, with the advent of our universal welfare framework, namely Social Security.

Part 1: Socio-historical Background

The Past

Today, long term care in the United States exists at the juncture of two major societal developments -- the aging of the population and the growing discontentment with traditional nursing home care. Improved medical technology, skyrocketing health care costs, personal preferences, and the fears of the elderly and persons with disabilities about nursing home placements have all increased the number of people either eligible for or seeking alternative care (Balinsky, 1994). Successfully restructuring long term care service delivery in America, however, requires an understanding of how the current situation arose, what went wrong, and which missteps can readily be avoided and which can not.

Long term care differs from the delivery of acute or episodic care which is time limited and aims to cure or prevent disease. By contrast long term care is on-going and encompasses not only the range of care received (or in some cases care *not* seen as being received), but also may affect how and where the person lives and the burden of care imposed upon the family and the community at large.

Historically, most long term care in America was provided by family members (Kaffenberger, 2000). And today, most long term support comes from family and friends (Tennstedt, 1999). But unlike today, in the 18th and 19th centuries, there were few instances of congregate or institutional settings for the elderly. Additionally, rapid industrialization and large-scale immigration during the 18th and early 19th century altered family structure and increased the number of individuals without recourse to family care. Orphans, widows with children, the mentally ill, inebriants, and the elderly were housed in locally funded poorhouses, designed to limit the attractiveness of public largesse (ElderWeb, 2006). Later, assistance programs provided by benevolent societies affiliated with ethnic, religious, trade, and profession groups multiplied and a scattering of corporate pension plans emerged. With the Great Depression, however, the limited number of corporation based pension plans collapsed, savings were lost, and public and private programs could no longer cope with the growing number of people in need of assistance. At that time, unlike other industrialized nations, the U.S. had virtually no coordinated safety net to address the dilemmas caused by a third of the nation out of work (Lowitt & Beasley, 1981). The federal government was called upon to intervene in social welfare matters that had traditionally been the domain of state and local government and the private sector.

Title I of the 1935 Social Security Act created a program, called Old Age Assistance (OAA), which gave cash payments to poor elderly people, regardless of their work record and provided a federal match for state old-age assistance expenditures ("Title I-Grants to States for Old-Age Assistance Appropriation, The Social Security Act (Act of August 14, 1935)," 1935). It was fabricated out of the 28 state old-age assistance programs that varied quite a bit, but that were mostly brought into the new federal system as-is. Each state was allowed to set its own standards for determining eligibility and payments, however, payments to anyone living in a "public institution" were forbidden. OAA is important not only because it set a precedent for a federal-state partnership that later spawned the Medicaid program but also because forbidding payments to public institutions. Although a well-intentioned strategy to starve poorhouses, this structure resulted in an exponential increase in the number of for-profit facilities catering to the increased numbers of older Americans with financial resources from the assistance programs. These facilities were built for the most part without regard to standards and without a guiding paradigm for long term care settings as differentiated from either poorhouses or hospital care.

In 1946, after World War II had halted construction on building hospitals, the Hill-Burton Act was enacted to provide federal financing for construction of new hospitals. In 1954, the Act was amended to provide funds to nonprofit organizations for the construction of skilled nursing facilities that met certain hospital-like building standards if built in conjunction with a hospital. Ironically, restricting funds to hospital-affiliated non-profits, which was intended to increase the quality of nursing homes, had the opposite effect. Developers who could not qualify for Hill-Burton funds continued to build thousands of new facilities with no reference to Hill-Burton standards.

When federal regulators would later decide that all nursing homes should meet the higher qualifications, it was too late. By the time Medicare and Medicaid legislation passed in 1965, the majority of nursing homes were functioning with low standards of service and relatively untrained personnel. Nursing home problems had become front-page news. Further, constraining funds to facilities meeting hospital-like building standards did little to distinguish either the setting or philosophy of long term care as being much different from hospital care. With a focus on building standards and duration of care, skilled nursing (or extended care) facilities were cast as extensions of the hospital environment with its medical model and culture.

From an historical viewpoint, it is important to briefly note the development of the health professions in relationship to hospitals. The respect for hospitals as treatment options for the general public as opposed to military events arrived late, in the early 20th century, with the advent of vastly improved effectiveness in many areas of health care, especially aseptic technique, drug therapy, pain control, and surgical and advanced technology. Prior to that time, most medical and nursing services were delivered to the home. For example, nurses were prepared to assist family members to learn how to take care of family members in the home (Nightingale, 1969/1860). Physician services were also home-delivered with the old-fashioned house-call. As urban settings expanded and more people were attracted to the promises of modern miracles in medicine, services and delivery mechanisms switched from home to hospital, and over time, people's lives were extended. Meanwhile, the tension between home and institution was growing because of the emphasis on acute care financing for all adults 65 and older (Medicare), with limited attention to long term care financing except for the impoverished (Medicaid).

Except for short-term rehabilitative care at home or in a nursing home, Medicare did not provide long term care services because of a fear that these services would financially devastate the program. Medicaid, on the other hand, required the states to provide nursing home care to the poor and new categories of eligible beneficiaries, such as the blind, disabled, and families with children. Coverage of nursing home services and only limited coverage of home care, however, created a perverse problem. If someone needed help and was unable to pay, they had the option of moving to a nursing home and receiving assistance where care costs were high. Families resorted and continue to resort to "spend down asset" tactics to assure their loved ones have access to long term care. Attention to mechanisms for alternate delivery of medical, nursing, and other skilled consultation to the home—as in the "good old days"—was becoming grossly overshadowed by acute care, institutional models.

By the 1970s, federal long term care policy began to shift with emergence of the rhetoric of individual choice and the independent living movement, which advocated that people with disabilities should have the same options and control over choices as do people without disabilities (Doty, Benjamin, & Franke, 1999). Deinstitutionalization of LTC services also became the preferred policy for older persons and, viewed as less costly than institutional care, a variety of home- and community-based waiver programs were initiated. In 1975, the states were given the option of offering personal care in the home, with less stringent

eligibility requirements than the 1915c Home and Community Based waiver program for participants deemed eligible for institutional placement (Takahashi, 2003).

To help states bring about infrastructure changes needed to remove barriers to deinstitutionalization, a variety of incentive programs were devised. Concurrently, foundations and nonprofits agreed to work together to develop new alternatives to institutional LTC. The move to reform long term care service delivery, however, took place at a time when New Deal social programs and government activism had come under attack. Thus, the menu of long term care reforms put forth placed heavy emphasis on individual responsibility and private solutions such as providing incentives to purchase long term care insurance, placing restrictions on asset transfers, and identifying those with the financial resources to share costs. The rhetoric of individual choice would serve to rationalize cost-saving strategies while government continued to overlook the fundamental basis or philosophy of long term care.

Today, federal regulations and oversight set stringent limits for long term care service delivery that are driven largely on a fiscal over philosophical basis. Nursing home reimbursements have been cut. At the same time, state governments are striving to control costs, especially for home and community-based programs. In 2002, responses from 76 percent of all state waiver programs showed that 57 percent used some type of financial cap, 33 percent used more restrictive financial eligibility criteria than for institutional services, and the vast majority of states limited the number of waiver slots available (Kitchener, Ng, & Harrington, 2004). In 2005, the national governors' association developed detailed recommendations for Medicaid reforms that would allow a reduction in service.

Recall the people in the introductory vignettes. A nursing home visit will affect each one of them as we expand on their stories throughout this article. Which of these people were being supported by Medicaid, private pay, Medicare or private insurance? Brian, recuperating from total hip replacement in a nursing home, was 60 years old. His visit was partially paid by private, gold-standard health insurance from a past employer. He illustrates several popular misconceptions, including the purpose and length of his nursing home stay (temporary and rehabilitative), the age myth (nursing homes are not just for the elderly), and assumptions about payer status. Many people are surprised to learn that there are younger people—much younger people—in today's nursing homes. In some states, there are even children in nursing homes. Further, Brian made an informed choice, deliberately based on his preference to recuperate in a nursing home rather than at home. This choice should not require surrender of other rights, controls, or simple pleasures, such as the availability of a preferred beverage.

About a third of today's nursing home residents are short-stay, following events such as hip replacement. For about another third, the nursing home truly represents a place where someone goes to die, as alternatives tend to keep people home longer until the intensity, expense, and the effectiveness of intervention becomes too much to reconcile in a private home. Further, Brian's choice of nursing home versus home care was a rational and informed choice. He and his partner felt that hiring home care assistance was invasive, threatening, expensive, and impractical, since Brian's needs were intermittent. For the short period of time that Brian needed extra help, a congregate setting with rehabilitative therapy and around-the-clock assistance seemed like a very practical and least restrictive way to recover. Private insurance and Medicare do not cover 24 hour availability of help in a private home.

The remaining third of nursing homes inhabitants have longer stays, for a median residence of 3 years, due to chronic and progressive conditions such as dementia.

The other two actors in our vignettes are not in a nursing home—yet. Bella, like many of her age cohort, is a middle class widow with a modest—even painfully shy—pension. She is actually on her way to “spend-down” to Medicaid coverage limits, as her needs for physical assistance will continue to increase, and her family resources have already been significantly eroded.

Last, Maria’s future nursing home costs will be paid by Medicare, Medicare gap insurance (again, a benefit from a previous employer), and if that brief coverage were to run out, private pay. However, despite ample health coverage (Medicare and Medigap insurance), and a substantial nest egg, she will still find it difficult to obtain a satisfying nursing home stay.

The Present

The call for abstracts for this special edition charged “imagine that we knew then what we know now.” How would nursing homes be different? First, we have to clarify what is currently known by a brief summary of recent and emerging LTC options.

What we know now, as opposed to then, is that there are many long term care options for the elderly, among them nursing homes, home care, assisted living, adult day care, adult foster care, and “waiver” programs or home and community based services (HCBS). In the private long term care sector, the assisted living industry, which has evolved over the past two decades to include a wide variety of settings and services, has rapidly become an attractive alternative to nursing homes (IOM, 1986). A major appeal of assisted living is its emphasis on choice and independence, which are basic premises of a socially-based long term care model. Other core values are expressed in terms of dignity, “home-like setting”, and ability to “age-in-place.” However, utilizing place-specific nomenclature to classify long term care options becomes ineffective when we critically examine the many places the elderly live, and the semi-permeable barriers to accessing acute, restorative, primary and supportive care services in either the private home, a congregate setting, or the nursing home.

We utilize the design and regulation of assisted living residences (ALR) as a case example of place-based inconsistencies. Assisted living is the most popular *congregate* LTC option operating according to the social model, and described as “an alternative” to nursing home residence. Assisted living is not only the most appealing option—it is the most confusing one to consumers. The regulations, restrictions and definitions of assisted living vary from state to state in the union—what’s allowed in one state is forbidden in another (Hawes, Rose, & Phillips, 1999). In some states, ALR regulations are highly prescriptive and in others, such as New Jersey, state law is very liberal.

For example, in Michigan, the authors’ home state, assisted living is considered a marketing term and has regulatory significance yet is not defined by statute. Any place may call itself “assisted living” and can choose to be licensed (if at all) as adult foster care or a home for the aged. Or, “assisted living” might exist as part of a continuum such as in a life-care of continuing care retirement community, parts of which might be licensed as Medicare and/or Medicaid certified.

Confusion about assisted living is not just localized, but one that crosses state lines throughout the union. We all know of situations where an older person and adult children reside in different states. The confusion and the resulting need for the challenging work to understand the referents implicated in such terms as “assisted living” or “nursing home” creates unique matrices of choices depending on which states are involved.

But is assisted living really an alternative, or a precursor to a nursing home? Many assisted living residences have stringent entrance and move-out criteria if a resident should become too needy. Some assisted living residences look just like nursing homes, differentiated only by a resident's closed door. Some people never have to move to achieve aging-in-place, while others will (Frank, 2001). Studies suggest that the core values of assisted living are hard to measure (Utz, 2003). Most disturbing is the inference that dignity, privacy, autonomy, and choice are commodities characterizing ALR setting, held as an alternative to nursing home care. Such verbiage implies that highly desirable aspects of personhood—e.g., dignity, privacy, choice—are tied to the setting one chooses.

While assisted living may seem like the most modern and popular option, this congregate approach to resolving the challenges of aging was developing in parallel step but in relative isolation from other emerging and attractive philosophies, home and community based waiver programs and person-centered planning. The assisted living movement capitalizes on the foresight or fortune of the middle and upper class, able to pay for services in a nice setting after retiring. The Olmstead initiative, disability rights advocates and the independent living movement, fought the narrow, undivided path to permanent nursing home residence for those whose private funds could not support other arrangements. All of the latter helped to promote the appeal of social model values as attainable only outside the nursing home.

And yet, despite the congregate setting and centralized services, assisted living is NOT to be considered an institution, like nursing homes. At the same time, the nursing home, the epitome of institutions, is also being “revolutionized,” with innovative approaches such as Well Spring, Eden Alternative, and Greenhouses. Greenhouses may resemble—on uneducated first glance, an incredibly integrated, resource rich adult foster care home. Greenhouses are built to express social model-values of choice, “home-like” setting, relationships, meaning, and support for autonomy. Tenets of the “Eden Alternative” are very similar to social model values, emphasizing “medicine as the servant of man, not the master”, and promoting choice, a stimulating environment with plants, pets and opportunities to strengthen interpersonal relatedness. “Edenized” nursing facilities can look just like some assisted living or adult foster care settings. One thing's for darn sure, in a Greenhouse or in a “home-like” setting, or an Edenized “facility”, or even in just a plain old-fashioned nursing home that individualizes resident care, you can get a cup of REAL coffee, and you don't need a doctor's order to eat a prune!

We return to the vignettes of our vision quest to further illustrate the inconsistencies in “place-based” LTC definitions. Only Brian's temporary residence is clearly labeled—a nursing home, and he will live there for only two weeks. Despite the resemblance to the stereo-typical image of a nursing home, Brian might have received a therapeutic and satisfying intensive rehabilitative fine-tuning in a “home-like”, or hotel-like, or even a resort atmosphere! In reality, all three of our sojourners (Brian, Bella and Maria) might be living in an assisted living residence, a continuing care community, a naturally occurring retirement setting (NORC), or be living a preferred lifestyle in a richer community setting, where their housing choice was based on amenities such as a vibrant urban and recreational district within walking distance. OR, be participating in a home and community based waiver program.

ARE YOU CONFUSED YET? If not, you haven't been paying attention! If the reader is a LTC provider, the confusion likely translates into frustrated and impeded attempts to practice effectively on any number of quality indicators. Imagine the complexity of the decision facing the naïve consumer, who research substantiates, rarely plans ahead and has great misunderstandings of long term care options (Floyd, Platz, & French, 2004; Harvard School of Public Health & Louis Harris & Associates, 1995).

PART 2: The true dilemma: The false dichotomy

With the emergence of various instantiations of nursing homes, assisted living facilities, and the confusion created from this variation, a substantial tension is embedded in this context. We argue that at the core of the long term care confusion is the false dichotomy of a social *versus* medical model. It is misleading to think of problems of aging as either one or the other. Medical problems and risks are real, increase with age, and can prevent social functioning. Further, there are two types of medical conditions that affect the elderly: chronic conditions (e.g., diseases such as dementia, or congestive heart failure) and acute problems (e.g., hip fracture) which can strike anywhere. How are long term care settings with an emphasis on a social model able to handle acute or chronic care requirements? On the other hand, are there persons unnecessarily in medicalized settings who could be living in other residential options?

Both social and medical models are incomplete and neither alone can guide the development of truly hospitable homes for the elderly. Pitched as a feverish battle between the medical and social models, the either-or dichotomy distracts us from the common realities facing elders across all settings. There are many challenges that result from this conceptual dichotomy. Over time, both regulatory and direct practice challenges have emerged.

Regulatory challenges

First of all, there is great variety in popular and statutory definitions across the 50 states. Additionally, there is great variety in understandings within any given state given the plethora and range of long term care facilities. These regulations include what is allowed or not allowed in terms of staffing ratios, and medical and supportive care available.

Another major challenge is that similar populations in terms of age, limitations, needs, can be found in all settings for the elderly. In other words, the client population suitable for different types of facilities is not strictly limited so there are a variety of persons with varying cognitive and physical functioning in many settings. Also, there is great variation in setting policies in terms of how to address needs of persons declining in certain ways e.g. dementia. At what stage or for what needs does the person need to transfer to another setting or are there ways to cater to their elevated needs?

Additionally, long term care facilities have become settings for persons of all ages facing serious challenges. For example, young adults and even children with certain disabilities may take up residence in long term care facilities. There are also older persons who engage with the long-term care system in a temporary way such as for prolonged rehabilitation or for some terminal conditions. In short, in the United States, long term care settings face serious challenges in regulating care and services offered as well as specifying which populations any setting is prepared to serve. We must ask, are all clients served in meaningful and supportive ways in our long term care system?

Direct practice challenges

There are also important direct practice challenges that we would like to highlight. For example, there is a serious practice of hiding decline and medical interventions in some long term care settings that propose to offer a social model of support. This is related to the tension inherent between “independence” and needing help. Health care providers are caught in the crossfire between social model values and medical realities.

Nursing is one discipline filling an ambiguous role in many alternative models for long term care, including assisted living and care management. Typically associated with the medical model, nurses are often seen as symbols of control and as icons of the nursing home (Moore,

2001). Some Assisted Living Residences therefore choose to camouflage the presence of nursing by hiding charts and medication supplies in what appears to be simply furniture. Nurses work “in cognito” in some Assisted Living Residences, blending in by not wearing uniforms. Moore (2001) suggests that for an Assisted Living Residence to be marketable and successful as seniors age in place, the connections between basic and more advanced care and nursing services need to be “seamless.” However, implicitly, do the seams need to be virtually invisible, lest fears of nursing homes be raised? Many Assisted Living Residences have no nurses on staff at all, while about 50% do, to various degrees and staffing levels (Hawes et al., 1999). Despite this variety, the final report of the Assisted Living Workgroup to the U.S. Senate Committee on Aging (ALW, 2003) is virtually silent on nursing’s role. Further, the role of nursing is under debate in waiver programs or other long term care settings, including care and case management.

One of the most difficult semiotic challenges is figuring out a way to separate nursing as a profession from the stigma associated with “nursing homes”. Nursing, like many other health disciplines, is valuable in all long term care settings. The availability of acute and medical consultation in all settings is also at the crux of debates seeking to define rules for residential, congregate or ‘institutional’ settings. However, the boundaries between temporary, acute settings and a home can be bridged by other methods, such as visiting physician and nurse services, or simple strategies like telemedicine and phone counseling.

Similarly, we know that medication assistance is a common and consistent service needed and provided in Assisted Living Residences. In practice, many Assisted Living Residences have minimally-trained or untrained nurse aides assisting with the provision of medications. Knowing the complexity of mixing medications for elderly, who may react to the combination of medicines in unpredictable ways, this practice based on ideologies of disassociation from a medicalized model, may lead to hazardous conditions.

There are additional workplace issues common to all LTC settings, whether the private home or ALR, or nursing home. For example, there are chronic and serious shortages of direct care workers (DCW), or nurse aides in all settings (PHI, 2002; Turnham & Dawson, 2003; Yamada, 2002). Recruitment and retention are chronic problems affecting facilities and home care agencies, linked to quality. The wages are low, the work is difficult, and there is little formal training. In a strange irony, a third to a half of DCW staff are themselves eligible for Medicaid (Turnham & Dawson, 2003). This raises issues of the “community” of long term care. Does that community include ONLY the individual participants? What about the broader community and society that provide the labor?

The broader professional community also has limited presence in LTC, compared to acute care settings. There are few nurses with advanced training in care of the elderly (Maas, Specht, & Buckwalter, 2002). Retention and recruitment of health care providers such as nurses to specializing in aging is hampered by the lack of emphasis on content specific to the needs of the elderly in most educational programs (Bednash, Fagin, & Mezey, 2003). The acute care model continues to reign supreme in health professions education, to the neglect of principles of rehabilitative services, aging issues, practical intervention in long term settings, as well as the adaptation of aging physiology and social issues in hospital and primary care settings (Maas et al., 2002). The acute care hospital model is based on a knowledge base of younger adult physiology and life-span.

However, there are unique attributes, health risks, symptom patterns, and economic and housing issues facing the elderly. The persistent neglect of emphasis in health professions education on support for the elderly is a puzzling feature of today’s health environment in the USA, given that the elderly are the fastest growing segment of the population, whose

health and housing needs are of front-page concern. Further, there is a huge language, culture, and educational gap between the research community and those at the direct practice level.

Maria and her husband live in a multi-generational high-rise within blocks of a lively and lovely downtown area in a geographic area conducive to outdoor walks to parks, senior centers, great restaurants, ubiquitous coffee shops and limited shopping. They have ample resources, both financially and environmentally. Even if they both survive to 100, it is highly unlikely that they would ever qualify for Medicaid. Despite their resources, they resist all pressure to pay for additional help, and Maria becomes increasingly isolated, inactive, and memory and other problems slowly increase.

Because of her advanced age, many friends and family assumed that Maria's memory problems and incontinence were only to be expected. An orthopedic surgeon suggested that Maria's falls were due to an arthritic knee, and recommended replacement. Her family were worried that the surgery would be too dangerous for her, but Maria insisted. Maria eventually got her wish. New-found mobility and security changed many things for Maria. She returned to daily walks to the park. Her memory and continence improved. Her short rehabilitative stay at a nursing home was flawed since, due to staff shortage, no one but the physical therapist ever got Maria up to walk. Her daughter had to get special permission from the doctor to walk with her mother even though she knew how.

In short, an accurate diagnosis and effective medical treatment ameliorated symptoms attributed directly to old age. The medical intervention improved her quality of life and reduced significant risk factors. That her stay in the nursing home was disappointing may have been due to short-staffing, untrained staff, restrictive policy, or fears of litigation.

Part 3: New Vision

In this article, we propose a new vision of LTC that addresses the common problems facing people of advanced age, and which accommodates the perspectives of multiple disciplines otherwise suppressed in medical or social models. We argue that the essential problem of defining, implementing, and regulating assisted living is due to an emphasis on *place*, rather than on a long term care *system*. We have shown several examples in the U.S. system of health care, where an emphasis on the models offered in a certain type of place where long term care created substantial gaps in quality care. Also, often, choices of long term care are conceptualized as requiring a *move* to a place. This approach is inadequate to meet the acute and chronic needs of the elderly, because the need for health services in an increasingly frail, aging population cuts across boundaries, housing types, and family and community resources.

We close with a call for a new type of interdisciplinary collaboration to design the future of long term care for the elderly, and to blend the best of both the medical and social models with emerging visions of quality of life. We conclude with a new set of core values, to be further refined and implemented by collaborative design between multiple disciplines at practice and research levels in gerontology (Rosenfield, 1992).

As starting points for design, we propose new core values. These new values will transcend place, eliminate skirmishes between medical and social models, dispel the unfortunate myths of aging and disability, and create a more integrated community and full range of choices for the primary beneficiary and family support network. These new values are synthesized from comparing ideals from assisted living with revolutions in nursing home care such as the Eden Alternative, Greenhouses, Well-Spring, as well as new ideas from disciplines less frequently thought of as important to the design of long term care.

Core Value 1: Transcend Place—long term care as a system

The first element in the new vision is to abandon construction of long term care as a place, or any multiple instances of places, on a continuum of solitary to congregate. This is of primary consideration in the design of a system that is able to transcend differences across a wide diversity of personal needs, resources, preferences and housing options, including urban, rural, and even cross-country communities. Emphasis on mobilizing the exchange of acute, medical, skilled, and long term supports and services across geographic and ideological boundaries will help to provide the greatest number of individualized options, clearer choices, and satisfactory outcomes in terms of quality of life.

The proliferation of assisted living facilities prior to the establishment of uniform standards is reminiscent of the earlier lack of government oversight of nursing homes, only with the pendulum swinging in an opposite direction, away from an emphasis on the medical model of care. To avoid foreseeable shortcomings, uniform standards that clearly define core principles of quality care desirable across care settings must be imposed. Moreover, regardless of care setting or the “model of care” without sufficient investment in quality and services the future of long term care can only repeat the mistakes of the past. The efforts of government officials and concerned citizens do make a difference; however, solutions do not come easily or without financial commitment. Creativity and flexibility are needed to be able to develop full range of options, especially those that get limited attention in discussions of LTC and housing options, such as “granny flats,” home modifications, and home sharing.

Core Value 2: Transcend medical/social divide with holism, or, “*Man does not live by meds alone.*”

Our vision also argues for a core value of considering every resident engaged in the long-term care system holistically. Residents are more than their physical needs or medication. So often, we see good care as attending to the medicalization component of a person’s stay in long-term care facilities. Every resident also has social needs including how to adjust to such a different living environment, with shared spaces and ritualized ways of being unique to each facility. Also every resident has social needs of how to make friends and build trust in this new space with other residents and with staff members. For the latter, relationships can be challenging because of the power imbalances and vulnerabilities that both sides bring to the table. The resident may be vulnerable in terms of physical and emotional dependence yet the resident is also the consumer, with the ability to lodge complaints.

A focus on holism also requires recognition of the most neglected families of disciplines with relevance for the new vision—the arts and humanities, including aesthetic expression and history. In addressing how to best promote a holistic view of every resident, we need to try to understand where each resident has come from, their relationships and their tastes and preferences. A holistic model is needed to transcend the historical pressures and biases affected by the acute care model on health professionals and patients and families as well as to overcome the myths of aging and disability, and to fully allow personal and interpersonal expression in finding meaning and relatedness.

Core Value 3: Transcend myths of aging and disability

There needs to be an adequate supply of experts readily available for consultation in all settings in order to effectively diagnose and remedy treatable complications of aging and disability. People working with the elderly need to know that there are differences in how older adults manifest illness. An untrained eye may overlook important clues (Amella, 2004). To consider the needs of the elderly as simply “custodial” or “basic” diminishes the complexity of human existence and the health risks that accompany this time of life.

Core Value 4: Transcend Traditional Disciplinary Boundaries

The pinnacle of “medical” achievement was identified with the new modern miracles of surgery, chemotherapy, and technology. Unfortunately, the medical profession was peaking at a time when Americans were becoming less and less tolerant of patriarchal decision-making about their health decisions—decisions in the short- and long-term settings. Concurrently, paternalistic traditions in society and health care were coming under attack. Although technology and medical advances caused and supported long term survival with serious disabilities, the acute care model failed to provide a good model of life with limitations. The development of health professions such as nursing, social work, and even medicine were heavily influenced and inhibited by roots in authoritarian societies. To retain the obvious benefits of advancements in both the research and practice disciplines in aging, a new framework is needed to guide inter-disciplinary collaboration and transcend historical prejudices against the desirable values of a wide variety of professional disciplines, and alternative approaches to health and wellbeing. Further, there is persistent influence of other social and historical influences on the provision of care to the elderly, chronically ill, or disabled, including socio-economic influences, and power differentials and dynamics among disciplines involved in providing health care.

Because of the turf battles and historical memories among members of the health disciplines, a new approach to interdisciplinary collaboration is needed (Formella & Rovin, 2004a). We propose “a conceptual framework for trans-disciplinary research [to] explicitly incorporate structures of society and bring into play all conditioning factors which influence the extent of health problems” (Rosenfield, 1992, p. 1351). The frailty, risks, and associated medical problems of old age exist in a social, cultural, economic and political context. In long term care, multiple disciplines may be dealing—cooperatively or in parallel isolation—with a complex health problem in situ, a societal health problem that materializes in the living arrangements of older adults. In the transdisciplinary approach, clinicians and researchers from various disciplines work together to synthesize a new, guiding paradigm for their collective work on a problem. A holistic systems approach involving cross-disciplinary collaboration is needed to confront and continually unravel the characteristics of history, culture, communities, economics and politics, on support services for the elderly (Formella & Rovin, 2004b).

The new vision needs to be created by a team of different disciplines from various sectors, and that can’t be broached until we can define the overlapping realms. We need to begin with a parallel notion to multi-disciplinarity, by developing a common vision within realms or sectors of society (Rosenfield, 1992), that fully utilizes the diverse resources brought by different disciplines. Health care in general in the U.S. is not yet at this point, since it is driven by the acute care model. There is a lack of coordination at leadership and practice levels to attend to both physical and psychosocial needs in various health sectors (Mechanic & Reinhard, 2002). We need to define the realms or sectors of society with relevance in this area—political? Economic? Health care and Housing?

The authors of this article represent a diverse group of disciplines (nursing, social work, anthropology, and political science), but we cannot advise on the specifics of the new trans-disciplinary vision. To foster cross-disciplinary collaboration at both the research level and practice settings, the following principles need to be considered. First, at the research level, disciplines concerned with gerontology come from both quantitative, qualitative, and humanities based research or educational paradigms. In order to communicate, all sides need to accept that by sharing perspectives, a better, unifying transcending model of long term care can be realized. Additionally, research about health remedies is primarily quantitative. The quantitative paradigm is based on concepts like population based statistics, while clinical practice needs to be highly individualized, and quality of life is highly idiosyncratic.

Further, “traditional” acute care medical science maintains a position of hegemony, with emphasis on drug therapy, surgical interventions, without encompassing alternative and complementary therapies, or the inclusion of recreational, social, esthetic activity as having merit in its own right.

In order for health professions and the LTC community to transcend the entrenched practices of the acute medical model, the new designers need to be able to critically examine disciplinary paradigms and allow for blended research and practice models that represent the full range of human experience and knowledge development.

Core value 5: Interdependence

Lastly, in our vision, we value interdependence. We must understand who is involved in the world of long-term care and that everyone is interconnected. The residents, family members, and staff caregivers all form multiple relationships in this system. By conceptualizing long-term care as a system, we understand that relationships have the possibility to surpass any one facility. This is not to say that given workload demands, the relationships will necessarily transcend places in large ways. What it does is open the possibility of the same caregivers seeing an older person through need-based transitions.

For in long-term care facilities, often residents and families form strong relationships with other residents, families, and staff. These new friendships often provide comfort to family members who can only have a glimpse on the world their loved one has entered. Often, it is these new friendships that help older people and their families cope with physical and emotional losses.

By understanding their histories which include their past experiences and interests/hobbies, we can aim to better facilitate their contributing in creative ways to their new environment. We can help persons feel a sense of purpose and value in their life in long term care and help create meaning for generations to come. Furthermore, the residents should feel some autonomy over some aspects of their life in the facility. There are many losses and impairments that residents face, yet there must be areas where choice is viewed as a right. A cup of coffee at any time, or allowance for a change in schedule when the resident requests may make the setting feel less like life runs them.

In a sense, the core value of interdependence continues to push the question about who is involved and benefited in the world of long-term care. In the largest sense, everyone is. Focusing on autonomy and independence of the labeled patient, beneficiary, or other-wise targeted participant of the long term care system, overlooks the impact of aging on others in a person’s social network (Hardwig, 1990; Schulz & Beach, 1999). Demands in any one age group of the family network have significant and long term implications themselves, such as negative economic and health consequences to adult children (who range in age from 40 to 90 themselves!) taking care of elderly parents (Ziemba, 2002). Every generation looks ahead towards how it will be to age in their society. Everyone is invested in the options available and how the care is conceptualized. Creating opportunities—regardless of the physical structures—for the interaction of families of origin and those of new formation is needed to create a sense of coherence, meaning and security in an age-integrated society.

It is our view that challenges in the vision of long term care arise from neglect of the barriers to realizing values such as dignity in the health care system itself, which has been heavily influenced economically and philosophically by emphasis on acute care treatment and financing, entangled in the specter of impoverishment that is represented in current Medicaid strategies.

In the new vision, Bella would not have to leave her apartment and move into a nursing home simply because she ran out of money. If her needs increased, the level of support would increase, or alternately, Bella would be able to move to another setting that provided more security, but that would not require sacrificing privacy or personal tastes. In either setting, knowledgeable health professionals would be available in case of emergency, for oversight and monitoring, and for coordination of treatment with other health providers, including discharge planners at hospitals. Physicians, nurse practitioners and other specialists would make house calls as needed, and hospitalizations and emergency room visits would be minimized due to early intervention.

Bella would live in an environment that she found engaging. While exercise class held no appeal, Bella would play ball for hours when the children from the day care visited. All around her, there would be interesting things to do or watch. She and her family could join others in activities. The staff—valued employees—would be in a good mood knowing that they could provide the attention that was needed and that they were compensated for their hard work. Where Bella lived would be supportive to her and to those that worked there.

Conclusion

We acknowledge that challenges in the long-term care system in the United States are both on the inside and outside. From within, we see the roles that workforce shortages, nonuniform regulations across states and misunderstandings of care options play. Our long-term care system is embedded in and reliant on other systems like Medicare and other health care systems, and retirement schemes. It is also a system embedded in an ideology of individual responsibility.

We have argued in this paper that we should begin to reconceptualize long-term care as a system, not a place. If we envision care beyond the walls of any institution, we realize that core values such as trans-disciplinarity, a holistic view of clients and interdependence are a starting point to this new framework.

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