# Nursing & Primary Care

# Spotlight on Nursing Home Care

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# ABSTRACT

Nursing homes often receive unfavorable press, [1,2] and this trend has intensified because of their involvement in multiple horrific COVID outbreaks [3,4]. On the one hand, high morbidity and mortality in nursing homes during the pandemic, apart from being a serious problem in itself, exposed ongoing inadequacies in the provision of quality care, which external supervision addressed only partially [5]. Running an effective nursing home is an expensive enterprise, which, unfortunately, is frequently underfunded [6,7]. Even with adequate funding, it is a complex endeavor at which it is not easy to excel [8]. On the other hand, as nursing homes are repositories for people with high morbidities whose health will invariably worsen over time, we may conclude that unmet expectations and unfortunate outcomes are not always preventable or the result of poor care. Nursing home care is not a government priority in the U.S., [9] and probably not in other Western countries either. This is unfortunate for many reasons, not least because of the likelihood that some of us will eventually end up in one. I believe that, while some criticism is justified, as nursing home care is sometimes suboptimal, in other cases there is inappropriate malignment. This paper will analyze how a nursing home works and attempt to distinguish between preventable and unpreventable poor outcomes.

# **Keywords**

Nursing homes, Financial viability, Humanitarian approach.

# Introduction

I am a Canadian-and Israeli-trained family physician who has been working part time in nursing homes both in Ontario, Canada and in Galilee, Israel, for over 35 years.

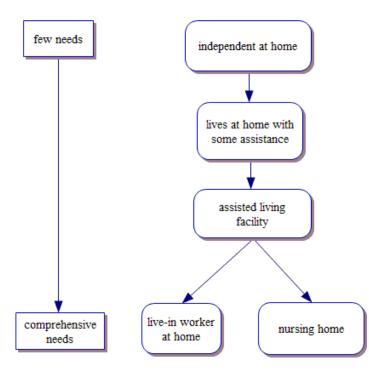
Around 4.5 percent (1.5 million) of older American adults live in nursing homes [10]. This is a large number, especially in view of the negative coverage, individual reluctance to enter a nursing home, family opposition to them, [11] and the stigmas often applied to nursing home staff [12,13].

# The structure and dynamics of a nursing home

Let us start with a definition and an understanding of what a nursing home is. Nursing homes are long-term care (LTC) facilities that provide comprehensive medical, nursing and personal care [14]. Most residents will remain there until the end of their lives.

The nursing home is a hybrid institution. In both Canada and Israel, the professional director is a physician. The institution is nonetheless termed a nursing home, and for good reason. In contrast to a hospital setting, where the patient's medical condition and need for physician involvement is the reason for admission. in a nursing home many residents are medically stable for long periods of time, while nonetheless requiring continual nursing care. The term "nursing care" here is used in its broader sense. While it may or may not include traditional nursing tasks such as dressing changes or frequent blood pressure measurement, it always encompasses continual daily help with the resident's personal care, i.e., the activities of daily living (ADL) [15]. The word home in the term "nursing home" is also important: Once residents are institutionalized, the institution becomes their permanent residence and their home, and good administrators strive to create an atmosphere that is personalized and homey. The ideal balance combines a home-like milieu with provision of the services and benefits that only an institution can offer.

Types of Institutions and the Needs they Meet



# **Characteristics of nursing home residents**

Nursing home residents are usually geriatric patients. These include the medically frail whose level of function is compromised because of some combination of chronic illness, multiple co-morbidities, or permanent disability [16,17]. They require round-the-clock supervision and attention to one or more of the following *basic* ADL parameters (BADL): ambulatory difficulties, transfers, toileting – both fecal and urinary – eating, bathing / showering, personal hygiene and grooming, dressing and undressing.

According to the CDC, 48% of nursing home residents suffer from dementia (2016), [18] while one third to one half of them will have a diagnosis of mental illness as part of their problem list [19]. In their advanced stages, dementia and mental illness often coalesce. An English study published in 2010 listed dementia, stroke, mental disorders, Parkinson's disease, and complicated diabetes – especially with amputations and blindness – as the main reasons for admission to a home [20]. Nursing homes are repositories for people who clearly cannot care for themselves without constant support.

Residents' personality quirks, behavioral complications of dementia [21] and/or mental illness and behavioral side effects of medication are common [22] and can interfere with effective provision of the care necessary to meet medical and nursing needs. Residents may be uncooperative, yell out for no treatable reason and be unpleasant to deal with. Behavioral issues such as agitation, which may be dementia related, [23] cannot always be controlled effectively by a combination of patience, good medical

and personal care by staff or calming medication. Nursing home workers can find themselves in the challenging predicament of trying to provide optimal care and treatment for an uncooperative and sometimes belligerent resident.

Family members, while often supportive and understanding, may have unrealistic expectations and/or be unappreciative [24]. If more than one family member is involved, they may not get along with one another, or not have the same expectations. Some residents have no family or visitors, which presents its own set of problems, especially around special events such as holidays and birthdays [25].

# Triggers for transfer to a nursing home

The two common sources of transfer are the home or a hospital. Admission from home is usually predicated upon a crisis, a series of crises, the final realization that the home option is inadequate, care worker issues, or a family member overwhelmed by the burden of care. Here is a typical narrative: "I knew it was time. During the previous nine months, my mother had been hospitalized three times for confusion, as well as for injuries from falls. It was clear to me she was no longer safe living alone in her apartment" [26]. There are many variations of this scenario, with the bottom line being that the individual can no longer adequately or safely cope at home. In recent years, the use of live-in home-care workers has enabled people to remain at home at a lower threshold of function. In difficult cases, however, a single home care worker may not be adequate to deal with a patient's multiple problems or able to provide the support necessary for a two-person transfer, for example.

Transfer from hospital is commonly due either to a medical condition, such as a new-onset CVA (stroke), or to general deterioration that precludes home discharge.

# The implications of being a nursing home resident, from the resident's perspective

Many residents have had to deal with accumulated losses – of spouses, friends, status, financial stability and more – before entering the nursing home. The multiple difficulties leading to transfer include physical limitations and significant symptoms associated with medical and nursing problems, together with age-related infirmities. Those who require help with toileting and showering, in particular, are faced with consequent loss of privacy. All these factors can impair a person's independence and sense of dignity [27]. In addition, transfer to a nursing home often occurs when residents are at their most vulnerable and may well be facing the most emotionally difficult period of their lives. We should not then be surprised if new residents appear overwhelmed, even if their cognition is intact and they have consented willingly to transfer.

# Stakeholders and their interests

Conflicting stakeholders and objectives coexist within a nursing home. These are the main issues:

 Financial viability ← → for profit: Some nursing homes are for-profit institutions, but even nonprofit alternatives require proper financial support and management to remain viable. Expenditures cannot exceed revenue, and there must be intelligent use of limited resources.

- Residents quality care and provision of service: A nursing home's mission and raison d'être is the provision of quality care and service for its residents. Adequate resources, professionalism in standards of care, compassion, time devoted to residents' needs and interdisciplinary cooperation are all essential to achieve this.
- Nursing home workers' professional and personal needs: Working conditions must be amenable to the provision of quality care: remuneration and working hours for everyone, including nursing aides, must be appropriate. Facilitating ongoing professional education can improve the workers' esprit de corps.
- **Family**: Family members expect provision of quality care. Involvement of families of nursing home residents is intrinsically different from family members' short-term role in a hospital milieu, where they sometimes, unfortunately, feel like a fifth wheel. Family members have both needs and expectations of the nursing home, and these should be addressed. When appropriately involved in the care of the patient, they have the potential to both improve quality of care and assist the caretaker team.
- i. When a family member is routinely involved, handling crises is generally easier. If a family member is kept up to date on a regular basis, he or she will be less surprised when a minor problem of which they had been kept informed takes a turn for the worse. Secondly, a trusting relationship built on regular contact between the physician and a family member can facilitate the handling of potentially difficult situations, such as a debatable hospital referral, as not all hospital referrals have clear-cut indications [28]. Thirdly, when possible, at least one family member approved by the resident should be involved in some of the value-laden decisions that need to be made – especially, but not only, when treating a cognitivelycompromised person – even if advanced directives are present.
- ii. Sometimes a difficult-to-solve behavioral problem that has occurred in the past and has been handled successfully by the family arises again in the nursing home; in such cases, family experience may be helpful in finding a successful approach to dealing with the issue.
- iii. Conversely, there may be problems, such as lack of resident cooperation, which neither the family nor the nursing home can deal with effectively. Such situations run the risk of being misappraised, causing the family to criticize the nursing home even though they themselves failed to cope with the same problem. However, when communication channels between nursing home and family work effectively, the family can often come to appreciate and understand the frustrations experienced by the nursing staff and may even commiserate with them. Moreover, family members suffering from a sense of guilt or inadequacy because of failure to solve the problem themselves feel vindicated when the nursing home reports a similar inability to do so.
- iv. Once a relative has been admitted to a nursing home, a family member can adopt a new role as the resident's advocate

(spokesperson), when necessary, especially in cases where the resident lacks the capacity to oversee his or her own care [29].

v. An additional complementary role is that of intermediary between the resident and the health system, particularly in instances where the resident is uncooperative or has unrealistic expectations of the medical system or nursing home. Here, again, family involvement can sometimes smooth things over and elicit resident cooperation.

In summary, open communication and active cooperation between the nursing home and family, while requiring some investment of time, can generate a win-win-win situation that best serves both the family and the nursing home team for the resident's benefit.

# Administrative leadership and a caring approach Administration skills

A functioning nursing home is a complex structure whose running requires the full spectrum of administrative skills: communication, decision making, problem management and financial knowhow [30]. My experience has been that the best nursing home administrators are those who can strike the optimal balance between sometimes conflicting priorities. Administrators who regard their responsibilities as a calling, rather than just a job, tend to be positively challenged rather than negatively overwhelmed when addressing such conflicts.



# A humanitarian approach

Running a nursing home with multiple residents is different from running a factory making multiple products. Whether or not the main purpose of the nursing home is profit, its task is to take care of vulnerable people in distress. Striving to ensure the financial viability and proper mechanical functioning of the home, important though it is, is simply not enough. A humanitarian approach to caring for the elderly and frail and looking after residents' welfare should be a fundamental precept [31]. Moreover, since providing this care is both physically taxing and emotionally draining, especially for the nurses' aides, and can lead to burnout, [32] provision of ongoing emotional support for workers by the administration is vital.

#### The initial period of adjustment

The transition from living at home for decades, and being in control of one's routine, to life in an institution is extreme and comes at a time when the elderly person can no longer cope effectively in the outside world. Dealing with the crisis leading to admission, adjusting to a completely different environment and schedule, and getting to know all the relevant workers and the nursing home routine requires time; traversing the successive stages of disorganization, reorganization, relationship building, and stabilization can take up to about 8 months [33]. The nursing home team likewise need time to get to know a new resident, a new family and the resident's idiosyncrasies. Patience is a prerequisite on all sides. My experience has been that it takes about 3 weeks for the family, and often the resident, to form an accurate impression as to whether things will work out well or not.

Changes may be instituted that differ from the admission orders. For example, as a physician I sometimes find discrepancies between the chronic medications as described in the last hospital discharge, on the list from the family doctor, and as actually taken by the patient. Establishing the best medication regimen can take time.

A related problem is that the medication prescribed may not accord with standards of care, and the physician needs to determine whether the inconsistency is deliberate or a result of suboptimal treatment. As an example, I recently admitted a resident suffering from dementia who has atrial fibrillation. The recommended standard of care is anti-coagulant medication unless the risk of bleeding is too high. From her history we learned that she had apparently seen a cardiologist, but no such medicine had been prescribed, and bleeding problems were not mentioned in the limited documentation we had at our disposal. Since no letter from the cardiologist was available on the day of admission, we could not establish whether the absence of an anti-coagulant was deliberate. Because of cases such as this. I find myself not infrequently making some changes to a resident's admission medication regimen only after the specifics of their condition have been clarified.

# The nuts and bolts of nursing home routine

#### Nurse's aide

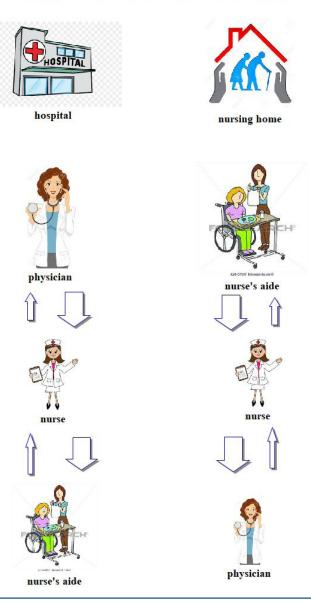
The brunt of care is typically provided by a nurse's aide, who undertakes most of the day-to-day personal assistance with ADL [34]. To succeed, such care must be performed professionally, and also with sensitivity and compassion that preserves the resident's dignity [35]. Residents will often comment, for example, on how gentle, sensitive and all too quick the care worker was when they were showered, rather than mentioning just the basic aspects of the cleaning process. Another example: some residents with eating problems will eat better when the care worker is patient and focused on finding the most effective and reasonable way to assist them (without compulsion) in eating their meal.

# Nursing home physician

The nursing home physician's role is different from that of the hospital physician. Because patients are referred to hospital with

a tentative diagnosis, are often unstable medically and usually have abnormal laboratory or imaging results, hospital physicians, if they choose, can work directly with the patient, independently of the nursing staff other than issuing medical orders. In a nursing home, on the other hand, when a problem does crop up, eliciting information directly from frail and debilitated patients can be difficult or impossible. The earliest indications of a developing problem may be subtle: agitation, decreased appetite and other mild behavioral changes or findings that fluctuate even in better times. Furthermore, a new problem may not always be associated with an abnormal diagnostic laboratory result. Just simply establishing whether a confused or demented patient is in pain can be problematic [36]. Therefore, the physician who strives to be effective in early diagnosis and treatment must work in synchrony with the duty nurse, as she, or one of the other workers who report to her, may be the first to notice a potential problem and call the physician's attention to it.

# **Dynamics of Nursing Home versus Hospital**



#### The multidisciplinary team (MDT)

As nursing home residents have less rehabilitation potential, the care-related goals of the multidisciplinary team members differ from how these professionals work either in the hospital or with people living independently at home. Emphasis is on optimizing and maintaining present function. For example, physiotherapy for residents who will never walk again independently should be geared to the provision of limited mobility (if possible), pain relief, staving off deterioration and contractures, and prevention of pressure sores. Multidisciplinary team members are often responsible for defining attainable goals: the physiotherapist assesses mobility and ambulation potential; a dietician, eating potential, especially in instances of weight loss; and the nurse determines the resident's potential for bladder and bowel control. The goal of nursing home care is to optimize the level of functioning of which residents are capable, without necessarily defining success by the attainment of a specific pre-ordained quantitative objective.

The adage *primum non nocere* (first, do no harm) is relevant to MDT work: the pharmacist, for example, can identify cases of over-prescription (polypharmacy) or the inappropriate use of medication; the dietician can assist in devising a diet that will maximize eating potential while minimizing the likelihood of aspiration for a resident with swallowing difficulties.

#### Unrealistic expectations of nursing homes

"Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" [37] *Susan Sontag.* 

At least some of the negative attitudes towards nursing homes stem simply from the fact that by definition, they deal with that swathe of the population least able to cope with the vicissitudes of aging and its related infirmities, whose condition will inevitably deteriorate over time [38]. While some residents and their family members may simply be disappointed by an inevitable worsening situation, others, due to unrealistic expectations, may be critical of the care received.

One form of unrealistic expectation is underappreciation of the complexity of a problem, its refractory nature (unresponsiveness to interventions), or expecting more than the institution's treatment team can provide. As the resident's condition continues to worsen, these unrealistic expectations may be manifested as emotional unwillingness to part from a loved one who, objectively, is dying [39]. Even though we shall all inevitably die one day, we human beings have always had difficulty accepting the fact. Today, when people live longer and there seems to be a new medical breakthrough every week, it is hardly surprising that some sick people and their family members are reluctant to accept the inevitability of deterioration and death [40].

# Pitfalls in the provision of optimal care

Following this analysis, some of the pitfalls that prevent provision of optimal care can be identified:

# Stakeholders and their interests

The various stakeholder interests may be under-addressed; if this is the case, the problem must be resolved. Should interests conflict, the administration should strive to find the optimal balance. When this balance is skewed, problems tend to arise.

# Funding

- Inadequate funding: Whether privately or publicly run, nursing homes need to be adequately funded. Judicious use should be made of the funding available. While the running cost of nursing operations should be easy to calculate, as in the nonmedical market, the cheapest solution may not be good enough.
- o Judicious use of a limited resource: Some operators tend to emphasize structural items, such as an impressive foyer, while underbudgeting running expenses. While there is no doubt that beauty and aesthetics add to the appeal and marketing potential of the home, they should not be provided at the expense of less conspicuous but vitally important resources.

Provision must be made for justifiable unexpected expenses. For example, at the start of the COVID pandemic, nursing homes were faced with a hitherto non-existent demand for masks, gowns, and other hygienic supplies. Those who lacked flexibility in purchasing these non-budgeted items were more prone to experience an outbreak associated with preventable morbidity and mortality.

# Nursing aides

All staff members should operate in professional conditions appropriate to the provision of quality care, and all should receive appropriate remuneration. Attention should be paid to the conditions of nurses' aides, as they bear the lion's share of the work burden and tend to be the most vulnerable members of staff. This point is crucially important and pertinent, as the quality of assistance in ADL is a major determinant in the overall quality of the nursing home care provided.

It is, however, unclear how assistance in ADL might be improved, as *research does not demonstrate unequivocally that this can be accomplished by improving aide training or staffing levels.* A Dutch review's conclusions regarding the quality of care provided by aides are unfortunately unclear: "While stakeholders believe intuitively that there is a positive relationship between staffing levels and quality in nursing homes, the research literature is contradictory." Furthermore, "based on four systematic reviews and individual studies, there is no consistent evidence of a positive relationship between the quantity of staff and quality of care" [41].

Regardless of these research findings, standards of care must be established, and work must be supervised. Where nursingaide training, employment conditions or salaries are suboptimal, problems will ensue. Many nursing homes are chronically understaffed, with nurses' aides being obliged to work long shifts in poor conditions. Consequently, absenteeism and worker illness abound, and quality of care is often compromised. Chronic understaffing and its associated problems were widespread before COVID, and their consequences intensified during the pandemic [42,43]. In summary, while neither improving the level of staff training nor increasing staff numbers has been demonstrated automatically to improve the quality of care for residents, understaffing and underpaying care workers has been clearly shown to compromise quality of care. During the COVID crisis this had catastrophic consequences in some nursing homes.

- Multidisciplinary team: Inappropriate and/or inadequate use may be made of the MDT, especially regarding residents who lack rehabilitation potential and thus may be unduly neglected.
- Use of a systemic approach: Dealing effectively with a problem often requires a process that involves a chain of events rather than just one step:
- i. A systemic approach to identifying problems: A nursing aide may be the first staff member to notice that a resident has a rash, or the social activity person may note that a resident is now sleeping through activities in which they were previously actively involved. This sort of information needs to be passed on to the duty nurse, and, when appropriate, to the physician.
- ii. A systemic approach to provision of care: Communication and coordination among the various strata and team members are essential. If, for example, the physician or dietician concludes that a resident's diet should be modified, change will be implemented effectively only if the message is clearly relayed to the aide responsible for feeding that resident.
- Supervision of nursing homes: As a nursing home is a complex functioning system whose residents are frail and vulnerable, it requires outside supervision, usually by a government agency [44]. Family-member involvement provides an additional surveillance factor, and, as mentioned above, family members can play a role as the resident's advocates, particularly when that resident lacks the capacity to assure that the quality of care they are receiving has not been inadvertently compromised. Ultimately, however, supervision should come primarily from within. Both the quality of care provided by the workers and the conditions necessary to provide that care need to be monitored continually as part of the administration culture.

# The advantages of nursing homes

- The preferred alternative: Typically, transfer from home to a nursing home is a consequence of either home resources' inadequacy to deal with the person effectively and/or the home caregiver's becoming overwhelmed by trying to meet the needs of a loved one. We may presume that even if the nursing home alternative was reluctantly chosen, it was selected because, all around, it was the best (or "least worst") alternative available.
- An impractical desire to remain at home / unwillingness to accept a new reality: For older people who inappropriately insist on living at home, home can become a restrictive prison that offers only suboptimal care and little to occupy them during the day. Even the few stairs that lead outdoors may be too much for them to cope with. An insistence on staying at home may be the misguided result of a yearning for youth, independence, health and what once was and no longer is. In contrast, a nursing home can provide a tailor-made framework which offers not only appropriate care but includes activities to occupy the residents

in their current condition. It is not uncommon, for example, to realize retrospectively that a resident living at home had been in a depressive state that disappeared once they adjusted to the nursing home, began interacting with other residents and became involved in social activities [45].

- The advantage of nursing home care over care previously provided by a family member, especially in complex situations:
- o Taking care of a relative at home can be onerous, and family members may face the complex and anxiety-promoting task of identifying and handling the patient's medical problems.
- o As people suffering from advanced cognitive decline or mental disorders will not always readily cooperate with a family member or homecare worker, unpleasant confrontations can result.
- o For people who are obese or suffer from paralysis, routine activities such as getting out of bed or showering may be unduly laborious.

Well-functioning nursing homes can provide an optimal setting that strives to combine a home-like atmosphere with the advantages of institutionalized care. The more complex and challenging the resident's needs, the less effective the stay-at-home alternative is, even with home support.

- Transformation of the family member's function From primary caregiver back to the role of relative: Once a patient has been institutionalized, the family member who had become the designated caregiver can return, at least in part, to his or her original family role, leaving both provision of care and responsibility for it mainly to the nursing home team.
- The potency of group activities: Group activities have tremendous supportive potential. Singing, arts and crafts, tailored lectures, holiday celebrations and cooking are common examples of activities that can work better in a group format. When watching our physiotherapist presiding over simple armand-leg group exercises or ball-throwing for patients suffering from dementia or mental illness, I never cease to be amazed at how our otherwise uncooperative residents often actively and willingly participate. In addition, basic routines, such as getting up, showering and eating, even when performed individually, may also work better with uncooperative residents in the momentum of a group environment, where they can observe others cooperating.
- Relative ease of dealing with acute medical problems: It is not uncommon for the elderly and frail to spike a fever, display a high or low blood pressure or sugar reading, or experience an undefinable episode of unwellness that requires an urgent medical assessment. For those in their own home, this may necessitate a trip to the E.R., with all the attendant complications of getting a wheelchair-bound and often confused person out of the house. In contrast, in a nursing home, such problems are dealt with by the duty nurse, sometimes in telephone consultation with the duty physician. When hospital referral is indicated, the nursing home will organize the transfer.
- Reduced need for hospitalization: Effective identification and severity assessment of an acute problem can lead to fewer hospital referrals and, subsequently, to fewer hospitalizations.

- o Appropriate attention to medical problems that crop up in the nursing home can reduce the frequency of unnecessary hospital referral and admittance.
- o Certain problems, such as some infections, may be amenable to parenteral (by injection or infusion) treatment either in hospital or within the nursing home. A hospital referral is avoided when the family  $\pm$  the resident, along with the physician, are willing to treat such a problem within an authorized nursing home.

When deliberating hospital referral – for any resident, and for a frail person especially – the nursing home physician must weigh the benefits of a hospital medical workup and treatment against the advantages of the nursing home's superior individualized concordant personal care. My anecdotal experience is that frail patients referred to hospital often do poorly, with a high prevalence of unexpected death or subsequent lower level of functioning, even when the referring problem has been properly treated. My explanation for this relates to the higher level of personalized concordant basic care<sup>36</sup> a nursing home can provide, in comparison to that of a hospital. (Nursing home) familiarly-provided individualized attendance to ADL would appear to have a strong therapeutic benefit, while its (hospital based) absence can create a therapeutic vacuum.

• Place of death: When death is inevitable, a nursing home setup can offer care that provides familiarity, comfort, symptom control, easy family accessibility and less risk of unrealistic or futile medical interventions.

# Summary

As our population ages and people live longer, accruing more and more medical problems, we can presume that the percentage of institutionalized elderly persons will only increase. When well run, nursing homes are often the best or "least-worst" solution for elderly people with complex and multiple co-morbidities. To succeed in their task, nursing homes require adequate resources and, especially, suitable employment conditions for nurses' aides. The administrator and administration have a responsibility to run the home competently, generate a caring atmosphere and strive for the optimal balance between the various interests and stakeholders, including appropriate family involvement. External government supervision should not replace internal commitment to the provision of quality care. Under even the best of circumstances, the processes of both living and dying at the end of life are not always pleasant, and the nursing home should not be judged only on resident outcome.

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