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PART I

Introduction

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1 *A framework for understanding regulation of long-term care quality*

VINCENT MOR

1.1 Introduction

Periodically, in most developed countries there are scandals reported in the press regarding poor treatment of frail elders living in residential care settings purportedly supervised by governmental authorities. While far more prevalent in the aggressive and adversarial legal environment in the US, scandals have been documented in England, Switzerland, Japan, Korea and China (Xinhua, 2005, 2007, 2008; Ferguson, 2012; Association TP, 2012). These instances represent an indictment of the regulatory bodies charged with insuring that adequate standards of care are maintained but also reflect the public outrage associated with authorities' 'allowing' such scandalous situations. Indeed, the outrage is as strong in countries where the regulation of elder care services is new as it is in societies where it is more established.

Such scandals violate social norms of filial piety, which are strong in most societies, but they also violate our expectations that the social institutions and arrangements we have come to trust have let us down, with significant consequences for the lives of the frail elderly who depend upon society for their care. Whether these expectations are warranted or not is not the point. However, they call into question our assumptions about how society should be meeting the needs of the frail and the elderly. Social commentaries on these scandals tend to have a particularly parochial perspective, assuming that the structure of regulation, oversight and financing of long-term care services that exist within a country are necessarily unique. Since failures to adequately care for the most vulnerable among us often are used as an excuse to make political or ideological points, the resulting discussions are often superficial without any real analysis of the fundamental assumptions underlying regulatory structures that govern long-term care service providers. However, demography and the different approaches that countries have adopted vis-à-vis financing long-term care have conspired to

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bring the issue of how societies assure the quality of those services to the forefront.

This chapter provides a framework for understanding the origins and regulatory structure of each of the country case studies included in this volume. After considering the historical basis of regulation in this sector, I review the functions any system of elder care regulation must address, followed by a discussion of the alternative regulatory philosophies and their application in long-term care. Since regulation is a quintessential government function, where the agency charged with regulating long-term care is situated with respect to the levers of power is an important characteristic of societies' investment in regulation, as is the extent to which it enlists the assistance of other social institutions like the professions and relevant non-governmental organizations in pursuing its agenda of assuring quality of care. Since the role of the market as a self-regulating force has received increasing attention in many circles, the chapter closes with a discussion of how market forces can reinforce, or counteract, the actions of the regulator.

1.2 Historical basis for the regulation of elder care

Conceptually, a regulatory apparatus consists of rules governing which entities, individuals or organizations can provide services of a particular type (Day and Klein, 1987). Most modern states govern which kinds of individuals and groups of individuals are allowed to assume responsibility for frail and impaired individuals thought to be unable to protect themselves from unscrupulous groups who might take advantage of their weaknesses. The state assumes responsibility for protecting such individuals for the same reasons it protects the public by requiring physicians to have a licence before they can minister to the sick by diagnosing, prescribing and operating. The informal caregiving network of family and friends need not have a licence to perform caregiving precisely because the state assumes that these informal relationships will have the best interest of the frail and impaired individual at heart. Things become more ambiguous when neighbours and others, not formally licensed to provide long-term care services, assume caregiving roles in exchange for either short-term or long-term economic considerations. Regardless of such ambiguity, the state has an interest in the regulation of transactions between individuals or organizations that purport to serve frail and impaired individuals since those

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individuals and their families may not be able to advocate for themselves (Braithwaite, 2002).

Historically, caring for the frail has been a family, or tribal, responsibility. Up until the time of the epidemiological transition and the beginning of population ageing, the prevalence of frail older persons in society was low and their survival time limited since neither the existing social structure nor medical knowledge were conducive to the extended survival of the elderly once they became frail (National Research Council, 1988).[1] As more older people survived to become frail, the challenge of caring for them inevitably fell to women of the younger generation as a universal obligation with innumerable exemplars from world literature. Only wealthier families were able to employ others to assist in this caregiving function. The notion that states would regulate who was hired to care for a family member was as unheard of as the state regulating the hiring and firing of domestic workers.

It is only with migration and population ageing, causing elders to be left behind to fend for themselves, that formal caregiving organizations arose. Obviously, societies have always included childless individuals, those incapable of earning their keep and/or who became impoverished due to illness, mental or physical. The Anglo-Saxon tradition of the 'poor house' or other community institutions filled that role as governmental or quasi-governmental entities serving a charitable function (Talbott, 1981; Brundage, 2002). In other European countries religious societies served this charitable function and even in the early years of communist China, local governments were charged with the responsibility of caring for the destitute, who were unable to work and who had no families. Societies' expectations of these facilities were quite limited and it was widely acknowledged that these were undesirable places, housing the least fortunate, who were, nonetheless, lucky to be receiving the minimal levels of care provided (Sherwood and Mor, 1980).

The rise of specialized facilities serving the frail elderly whose families could not care for them emerged largely from sectarian traditions in most Western societies (www.elderweb.com/book/export/html/2806). Catholic charities, Lutheran homes and Jewish homes for the aged,

[1] The epidemiological transition began when infectious diseases were no longer the primary cause of death and chronic illnesses such as diabetes and heart disease became more prevalent as a higher proportion of the population reached advanced age.

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along with various 'benevolent societies', emerged in the latter part of the nineteenth century, providing culturally focused residential services sustained by community philanthropy and private fees paid from residents' savings and families' income. In Switzerland, local monasteries operated 'hospices' which included care for the elderly but gradually local communities (cantons) took over these functions. Like hospitals which preceded them, the emergence of this class of service providers was accompanied by the development of some form of licensure, even if only because the facilities served meals and had to comply with public health and hygiene laws. In parallel with this more formalized approach to elder care, in most communities an informal market of caregivers arose among landladies or boarding home operators, who increased their level of service as their elderly boarders grew more frail, or among housekeepers, who provided personal care in addition to cooking and cleaning. To the extent that such informal arrangements became more public or commercial, they could have been subject to licensure, but rarely were.

Societal ageing, falling birth rates and geographic and economic mobility among the young, particularly to urban centres from villages, resulted in elders increasingly living alone. In Spain, over the last several decades, the proportion of the elderly population living alone has nearly doubled and China's one-child policy has only reinforced this natural tendency toward urban migration. The net result is that the elderly are increasingly living outside of traditional multi-generational households in rapidly modernizing countries like South Korea, Japan and China. Even in Germany and other European countries that went through the demographic transition some time ago, the proportion of the population over 65 has exceeded 20 per cent and many of these individuals live alone.

While not universally true, the movement from informal arrangements to more formalized regulatory structures seems to be accelerated when governments begin to finance these services. Financing can refer to either construction assistance or operating subsidies in the form of payments to residents (and therefore to providers) or both. For example, in the US, when state and federal governments wanted to stimulate the supply of nursing home beds, low-interest loans were made available and the cost-based reimbursement system served to encourage many to enter the market as long-term care providers. Interestingly, China, which has a limited institutional long-term care system which

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the government would like to expand, also offers two approaches to supporting nursing home providers: first by offering a financial subsidy per bed built and secondly by subsidizing providers per occupied bed, irrespective of the wealth or need of the resident. Regardless of type of financing support, social expectations of these services change because of the change in the behaviour of providers in response to the availability of funding for activities that had previously been undertaken informally. Indeed, the impact of public financing alters the market quite dramatically; in most societies that have instituted some form of public financing for long-term care a new group of providers enters the mix and the existing providers alter their activities in order to become eligible for public support. This growth of long-term care providers has generally been the stimulus for wholesale revisions to regulations designed to assure the quality of care frail older persons receive, at least partially, to insure that public funds are properly spent.

1.3 The structure of regulatory functions

A useful heuristic device is to divide the regulatory functions that govern long-term care providers into three broad domains: 1) standard setting and initial inspection and licensure; 2) ongoing surveillance and enforcement; and 3) reporting and/or rewarding performance. Each function has various components, which vary both in structure and approach, as will be evident in the country studies included in this volume. The structure of a country's regulatory function is informed by a philosophical or ideological position regarding whether the regulator acts as the police monitoring compliance or as a partner striving to achieve the ultimate goal of assuring quality.

Establishing Provider Standards determines what it takes to be able to offer long-term care services to the public and includes how the provider goes about obtaining a licence. In many professional fields like medicine and nursing, the state delegates to the profession the task of setting standards precisely because they have the expertise to determine what the standards should be (Kovner and Jonas, 2002). Thus, medical professionals are generally granted licensure upon completion of the agreed-upon educational requirements that were established by the profession itself. Since historically elder care was a social and/or residential service rather than a medical service, setting standards for long-term care services was not delegated to established medical

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professions. Rather, regulations governing standards for issuing a licence were formulated by a combination of professionals, advocates, engaged politicians and representatives of the provider community. While national regulation of long-term care is relatively young, England has had regulation since 1927 under a social welfare model. However, as the needs of those receiving long-term care evolved and become increasingly medically complex, the weight given to clinical issues versus social issues often changes the standards and requirements for being a long-term care provider. In some instances, different regulations apply for different kinds of providers depending on the types of residents served and the range of services provided.

Standards commonly address the structural features a provider must meet in order to obtain licensure. These include aspects of the physical environment ranging from fire and safety concerns to room size and services and common space available as well as the number, training and education of the staff caring for the service recipients. Standards may also dictate specific processes of care that providers must ensure, generally related to the documentation of services rendered. These can take the form of documenting the frequency with which staff apply creams and/or turn bed-bound residents to prevent pressure ulcers. In some instances standards may also offer patient outcomes to which providers should aspire, such as the ‘maximum rehabilitation potential’ enshrined in the US Nursing Home Reform Act of 1987 (Institute of Medicine, Committee on Nursing Home Regulation, 1986). Patient outcome domains of salience can range from clinical care provided, such as the occurrence of skin pressure ulcers or uncontrolled pain, to quality of life or even satisfaction with the quality of patients and/or their family members’ experience. In this way the patients’ experience can become an integral part of the quality assessment process, in spite of the many technical challenges associated with doing this well (Mor, 2005).

In addition to establishing standards that providers must meet, regulations also stipulate how applications to become licensed providers are reviewed and inspections are to be undertaken as part of the licensure and certification process. In some cases the first step in obtaining licensure is to prove that there is a need for the service, irrespective of whether standards are met. Depending upon numerous factors, in some instances the state may have an interest in restraining the supply of services, either to minimize duplication or to stimulate demand, that is

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thought to ultimately end up costing the state more than would otherwise be the case (Rivlin et al., 1988). While the wisdom of policies designed to constrain supply has been questioned, the state does have an interest in ensuring that only qualified providers receive licensure and/or certification. As such, the application process along with the associated review and on-site inspection can be prolonged with multiple steps in the process. In those countries in which licensure or certification carries with it the right to seek reimbursement for eligible service recipients, the oversight and review process necessary before a licence is granted may be even more tightly controlled. Indeed, in countries like Germany, Japan, England and the US requirements for payment are commensurate with quality regulations.

In some instances licensure or certification may be provisional for some period of time to allow for ongoing observation of how the provider operates and meets residents' needs. In order to begin serving frail older persons an operator must have a licence but inspectors can only observe care being delivered *after* the licence is issued, making it reasonable to grant provisional licences. The rush of applications that frequently accompany wholesale regulatory changes can result in a backlog of provider applications which, without a provisional licence, means that providers' investments in staff and facilities cannot be recouped since no residents can be admitted. In England, there is a requirement that the regulatory agency must conduct a complete inspection within a fixed period of time following the filing of the application, but in actuality this can be more prolonged.

Nonetheless, once a service is operational it is as difficult to close it even after only several months of operation as it is after several years, since individual service recipients will necessarily experience the disruption of a transition to a new provider. Unfortunately, since a flood of new providers often enters the market immediately following the introduction of long-term care financing, the time and effort needed to scrutinize prospective providers are frequently unavailable just when they are needed most. It is for this reason that standards are often adhered to more rigidly in the initial application process than in subsequent inspections. This means that there can be a fine line between standard setting and initial inspection and the next stage of ongoing monitoring and enforcement.

Ongoing Monitoring and Enforcement represents a broad range of functions and choices, ranging from the frequency and scope of inspections

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to the means by which sanctions are applied and whether and how they can be appealed. Monitoring of providers' compliance with standards theoretically begins as soon as the licence is issued, but in actuality it begins when the first repeat inspection is undertaken. The frequency with which inspections are conducted is generally explicitly mandated in regulations. In some instances, inspectors have the discretion to inspect providers that have a good record less often and to inspect chronically poor performing providers more often. In view of the substantial costs incurred by the regulator and provider in preparing for and executing an inspection under most regulatory regimes, more frequent inspection is viewed as a significant adverse event.

The composition and character of the inspection team is also relevant. While most inspections are conducted by teams, almost invariably one of these individuals is an experienced nurse familiar with long-term care services. Other professionals included might be someone with a background in environmental engineering or a dietician or long-term care pharmacist. It is often the case that inspections are supposed to be unannounced, even though they tend to occur around the anniversary of the previous one. In some cases it is desirable to alter the composition of the inspection team between inspections to insure a 'fresh' pair of eyes, but that may depend on the enforcement philosophy and the range of alternatives available.

The literature on regulation differentiates between compliance-based and deterrence-based regulation, with the latter focused on rigid adherence to the precise strictures of standards while the former adopts more of an informal dispute resolution approach (Day and Klein, 1987). It is during the inspection process that this difference in philosophy is most apparent since adherents to the deterrence approach would necessarily follow a much more formalized inspection protocol. Indeed, the centralized US Medicare/Medicaid nursing home recertification inspection process (even though delegated to the states) has become increasingly proscriptive over the last several decades, precisely to minimize individual inspector discretion. While the advantage of this approach is greater specificity and explicit focus, some believe that it results in compliance with the 'letter' of the law rather than with its spirit since the latter cannot be 'observed and documented'. Indeed, some would argue that the natural result of the deterrence approach is a counting game that serves no real purpose and does not necessarily translate into superior quality (Day and Klein, 1987). On the other hand, the disadvantage of

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