

Regulating Long-Term Care Quality

The number of elderly people relying on formal long-term care services is dramatically increasing year after year, and the challenge of ensuring the quality and financial stability of care provision is one faced by governments in both the developed and developing world. This edited book is the first to provide a comprehensive international survey of long-term care provision and regulation, built around a series of case studies from Europe, North America and Asia. The analytical framework allows the different approaches that countries have adopted to be compared side-by-side and readers are encouraged to consider which quality assurance approaches might best meet their own country's needs. Wider issues underpinning the need to regulate the quality of long-term care are also discussed. This timely book is a valuable resource for policy makers working in the healthcare sector, researchers and students taking graduate courses on health policy and management.

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Foreword

A key but neglected issue in long-term care is how different countries ensure that nursing homes, home care agencies and residential care facilities provide good-quality care. Although countries employ a number of strategies to accomplish this goal, the most common approach is regulation – to establish mandatory, government or government agent-imposed quality standards (Wiener et al., 2007a, 2007b). In most cases, these government regulations or other standards set the minimum quality that providers must meet to operate or to receive government funding. The role of government regulation in long-term care varies widely across countries, within countries and across services. In most countries, long-term care is heavily financed by the public sector (European Commission, 2012; OECD, 2005). Thus, governments have a fiduciary responsibility to ensure that the public's money is well spent. This book fills an important gap by analysing how a large number of countries around the world regulate the quality of long-term care services and the extent to which they make the results of their inspections and other information on quality available to the public.

Although some countries, such as the United States, have well-established regulatory systems, others, such as China, do not. But having a well-established regulatory system does not guarantee that all providers establish high quality. For example, in the United States, 23 per cent of nursing homes in 2010 were cited for causing actual harm or placing residents in jeopardy (Harrington et al., 2011). Moreover, during that same year, the US Administration on Aging received 157,962 complaints from nursing home residents or their families about poor quality of care, problematic quality of life and violations of resident rights (US Administration on Aging, 2011). Additionally, almost nothing is known about the quality of residential care facilities

because these providers are regulated at the state level using highly variable standards and the provision of personal care by home care agencies and individual providers is hardly regulated.

The regulatory process has three components: (1) rules that establish the standards or norms that providers must meet; (2) inspections or other means of collecting data to assess whether the providers are meeting the rules or performance norms; and (3) enforcement or other remedies to address problems identified during the inspection or other discovery process. How countries implement these three activities varies widely. Reflecting the historical emphasis on institutional care, such as nursing homes, regulation of institutions is more common than regulation of home- and community-based services.

Although ensuring quality of long-term care has always been important, its salience will grow rapidly in the coming years because many more people will receive long-term care services and because government expenditures to pay for those services will increase substantially (European Commission, 2012; Johnson et al., 2007; OECD, 2006). Throughout the world, the population is aging. People aged 80 and older, who are most likely to be disabled and need long-term care services, are among the fastest-growing segments of the population. For example, for the twenty-seven countries in the European Union, the population aged 80 and older is projected to increase 2.6-fold as a proportion of the total population, from 4.7 per cent of the population in 2010 to 12.1 per cent of the population in 2060 (European Commission, 2012). The ageing of the population in the developed countries is well known; much less appreciated is that the population in middle-income countries is also ageing rapidly. Indeed, the proportion of the population aged 85 and older in Brazil, China, India, Mexico, and Russia will more than quadruple between 2010 and 2050, bringing them to at least the 2010 level of the United States or higher (US Census Bureau, 2009).

The critical role of government regulation in long-term care is related to the types of services provided and the people who use those services. Regulation is used cautiously in most free-market-oriented economies, yet quality assurance for long-term care is an area dominated by regulation. The rationale for the prominent role of regulation in free-market economies is market failure such that consumers cannot effectively use their market power to improve quality.

First, many people using long-term care services are severely ill and disabled, and some of these individuals may not have the ability to complain about the care they are receiving or to ‘vote with their feet’ and use another provider. Moreover, many people who require long-term care services have cognitive impairments that make it difficult for them to make decisions. For example, in the United States, 41 per cent of nursing home residents in 2009 had moderate to severe cognitive impairment and 68 per cent of nursing home residents had some level of cognitive impairment (US Centers for Medicare and Medicaid Services, 2010). Finally, some people using long-term care services have no close family or friends to act on their behalf for their care and protection, if needed.

Second, nursing homes and other residential settings, in particular, are ‘total institutions’, where individuals live twenty-four hours a day and where many aspects of life are controlled by others (Goffman, 1961). Fear of physical abuse and other retribution from staff may prevent residents from complaining, and difficulty finding other placements may prevent them from leaving. Even for home care, people with severe disabilities may suffer adverse consequences if they are left with a gap in service caused by ‘firing’ their personal care worker (LaPlante et al., 2004).

Third, although a great deal of long-term care is non-technical help with activities of daily living or instrumental activities of daily living, many providers serve individuals with substantial healthcare needs that require medical skills that laypersons are unlikely to be able to evaluate (Walsh et al., 2012). Fourth, high occupancy rates in nursing homes and a shortage of home and community-based services providers in many countries may mean that providers are able to operate at near capacity without having to compete based on quality of care. This may be especially true of providers serving beneficiaries of programmes designed for the poor, which often have lower reimbursement rates. In these situations, consumers cannot choose another, higher-quality provider because there are none available.

Finally, decisions about the appropriate type of care and which provider to use are often made more difficult by the need to make decisions quickly while under substantial stress. Thus, placement in nursing homes is often done during a rushed period when hospitals are seeking to discharge patients so that they can free up beds, making the choice of long-term care services less deliberative and careful. In

addition, because relatives often want services provided at a geographic location close to them, the choice of facilities or other services may actually be quite limited, again lessening the amount of effective competition.

Issues in the design of a long-term care regulatory system

In designing regulatory systems for long-term care, countries must address a number of important issues, including defining what is meant by quality, deciding which providers will be subject to the regulation, establishing quality standards, providing incentives for providers to do more than meet minimum standards, obtaining timely information about the quality of care provided, enforcing regulations in a way that obtains compliance and deciding what information about regulatory performance should be made available to the public.

Given the characteristics of long-term care, the domains of quality are often divided into quality of care and quality of life. Although related, these domains are analytically separate and address separate parts of the care experience. In terms of quality of care, a major focus of long-term care regulation in the United States is on health and safety, including potential markers of poor quality such as dehydration, urinary tract infections, malnutrition, bedsores, excessive use of hypnotics and anti-psychotic medications, undertreatment of depression, weight loss and uncontrolled pain. For example, quality of care assessments include whether nursing homes carefully help residents with eating, whether there is adequate staffing to assist residents at mealtime and whether residents maintain an appropriate weight. The vast majority of existing regulations and quality measures focus on quality of care.

In contrast, quality of life refers to much more intangible factors, such as autonomy, dignity, individuality, comfort, meaningful activity and relationships, a sense of security, and spiritual well-being (National Citizens' Coalition for Nursing Home Reform, 1985; Noelker and Harel, 2000). These factors are, by definition, subjective, but they are critical to living a good and meaningful life. For example, quality of life refers to the tastiness of the food, the ability to choose meals that fit with personal preferences and ethnic heritage, the friendliness and patience of the staff helping with feeding and the willingness of the staff to let residents feed themselves to the extent possible, even if it takes additional time.

An important hypothesis articulated by some advocates of assisted living and consumer-directed services is that there may be a trade-off between quality of care and quality of life (Kane, 2001, 2003). Kane (2001) argues that for most people a meaningful quality of life is more important than health and safety. Thus, for example, an individual with diabetes at the end of life may want to eat candy because it tastes good, even though doing so is medically undesirable. The negotiated risk agreements in some assisted living facilities in the United States, where informed consumers or their agents explicitly accept risks and the possibility of adverse outcomes to achieve quality of life goals, are an effort to address these trade-offs (Jenkins et al., 2006).

Almost all countries devote far greater resources to monitoring nursing homes and other institutional providers than they allocate to home care and other community services. Reflecting funding limitations and the greater vulnerability of people in institutions, it also reflects the greater difficulty of regulating quality in home- and community-based services: the range of services is great with a great multiplicity of types of providers; users are, by definition, highly geographically dispersed, making data collection difficult and expensive; and there is less consensus on what the standards should be. In the United States, this lack of consensus is exacerbated by a belief by some policy analysts that nursing home standards are rigid and interfere with quality of life; thus, there is a strong policy desire not to replicate those standards in the home- and community-based setting (Kane, 2001).

A key task is establishing the quality standards that providers must meet. In the United States, federal and state regulations emphasize inputs, manuals, paperwork and structural capacity rather than resident outcomes. Critics contend that regulations are usually not evidence-based and do not measure what is important. These observers blame much of the poor quality of life in nursing facilities on rigid regulations, which force a ‘medical model’ on nursing homes.

A major element of the political economy of regulation is that many proposals for improving the quality of long-term care – for example, requiring higher staffing levels – require substantially more financial resources than governments are willing to spend. Thus, providers contend that it is unfair for governments to insist on high-quality care when they are unwilling to pay for the staffing and other inputs necessary to make it happen.

Most regulations establish the minimum that providers must do; in other words, they set a floor on provider activity. Opponents of stricter regulation also argue that detailed rules stifle innovation, with few incentives for doing more than the minimum. The dilemma is how to give good-quality facilities more flexibility while still requiring substandard facilities to meet adequate standards.

Setting standards is important, but standards are meaningless unless regulators are able to monitor how providers are performing against them. In many countries, regulators often do not have adequate resources to even visit all providers on a regular basis. The United States, for example, had 15,678 nursing facilities in 2012 (American Health Care Association, 2013), 31,100 residential care facilities in 2010 (Park et al., 2011), 10,581 home health agencies in 2009 (National Association for Home Care, 2010), and an unknown but large number of non-skilled home care agencies and consumer-hired individual personal care providers, making just visiting providers a daunting task. Infrequent visits mean that providers may perform when visited by regulators, but provide substandard care when government inspectors are not around. Limited funding for inspections in many countries means that providers are visited infrequently, raising questions of how effective the monitoring oversight can be. The infrequency of the inspections has led consumer advocates to argue for more resources and to search for strategies that do not depend on the constant presence of inspectors.

Different countries have adopted varying strategies to enforce regulations. However, without enforcement, the standards are meaningless. For some countries, such as the United States and England, enforcing regulations is a classic policing function in which providers who do not meet the regulatory requirements are identified and punished. In other countries, the relationship between providers and inspectors is more collaborative and the role of inspectors is more to work with providers to resolve problems. Advocates of strong government regulation argue that enforcement remains too weak and that stronger regulation would greatly improve quality of care.

Although regulatory sanctions are meant to punish the owners or administrators of poor-quality nursing facilities, it is hard to avoid ‘punishing’ the residents at the same time. For example, closing a facility may require the relocation of a large number of residents, which is hard to achieve because of relatively high nursing home occupancy rates in most countries, and which will cause disruption to residents’ lives and

social relations. Likewise, ‘intermediate sanctions’, such as freezing new admissions or imposing civil fines, may result in reduced cash payments to facilities that may need to be spending more money on staff and other services. This inability to separate nursing homes from their residents is a major constraint on the willingness of regulators to impose tough sanctions on poor-quality facilities.

One increasingly prominent approach to improving quality of care is to provide more information to consumers, their families, providers, hospital discharge planners and others about the quality of individual long-term care providers (US Centers for Medicare and Medicaid Services, 2012). The underlying premise is that the lack of information on quality results in a market failure. The basic assumption of this approach is that, armed with more information about quality of care, consumers will choose high-quality providers and avoid poor-quality providers. Thus, in theory, market competition for residents and clients would force poor-performing providers to improve their quality of care or go out of business. Hospital discharge planners, case managers and others involved in the placement process could also use the information to advise individuals needing services and their families. Providers could also use the information to identify areas for improvement. Many countries are now exploring this strategy, although providers generally resist releasing information to the public about the performance of individual providers. Although there is widespread support for providing more information to consumers, the research literature on the consumer response to quality of care information for long-term care finds only modest positive effects (US Centers for Medicare and Medicaid Services, 2012).

Conclusion

For people who use long-term care services, the quality of the care they receive is critically important, and in some cases can be the difference between life and death. Too often, quality of care is like what we ourselves would want to receive if we needed care. Government regulation is one strategy to try to ensure that all providers supply at least a minimally adequate level of care. Throughout the world, these strategies are evolving, and in many countries expanding to home- and community-based services that were never before regulated. This book provides an invaluable examination of how fourteen countries regulate

the quality of long-term care services. The hope of cross-national analyses is that countries will learn from each other and improve services to people with functional and cognitive impairments who need long-term care services.

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¹ RTI International is a large, non-profit research institute in the United States.

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