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COMMENTARY

Perspectives on regulating long-term care

Commentary on "Regulation of long-term care for older persons: a scoping review of empirical research" by Pot *et al.*

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Organizing sustainable and accessible high-quality long-term care (LTC) is a unprecedented challenge for health and social care (ILO-OECD, 2019; OECD, 2018). The rapidly rising numbers of "oldest old" (people 80 years and over), combined with the oldest old being more prone to complex multiple conditions, lead to an fast-increasing demand for LTC (Beard *et al.*, 2016). Alzheimer's disease and other forms of dementia are among the most impactful drivers for the resulting pressure on professional and informal care (WHO, 2021; Wimo *et al.*, 2023). Further, the potential supply of labor force in the vast majority of G20 nations is declining, partly because of an aging workforce. Significant staffing shortages are already a widespread everyday reality (EC, 2022; OECD, 2021; Spasova *et al.*, 2018). On top of that, expenditures on LTC, and in particular dementia care, are rising at the highest rates within the health care sector (OECD, 2021; Wimo *et al.*, 2023).

Unsurprisingly, quality of LTC including dementia care is at stake (Spasova *et al.*, 2018). The quality of care in LTC services is already poor in many countries (OECD, 2018). (LTC) settings are often ill-suited to caring for people with dementia and/or other impairments. LTC services are often provided by services that were originally designed for curing diseases and not for supporting the vulnerable physical, mental and psychosocial capacities. Furthermore, services are in many cases ill-resourced (OECD, 2021). Care workers are often poorly paid, have limited education, and have in many cases highly fragmented contracts. A large part of care delivery rests on informal carers (EC, 2021; Eurofound, 2020; OECD, 2020). In addition to that, professional care in people's own homes is often weakly developed (Spasova *et al.*, 2018).

The current health paradox is that the better our health care, the more multiple chronic conditions we have to deal with. A well-functioning and comprehensive LTC system is therefore of indispensable importance to current societies (Beard *et al.*, 2016). However, quality of LTC systems, including dementia care, deserves relatively little attention in policy making and research. Only when scandals are brought to public attention (e.g. Barron and West, 2017; Miller *et al.*, 2012) or crises such as COVID-19 occur (e.g. Koopmans *et al.*, 2022), there is some societal awareness that quality of care and quality of life are not self-evident in the LTC sector. Thus, assuring and improving high-quality care will be increasingly important, if not, an essential necessity in LTC systems.

There are many ways of assuring and improving quality of LTC. Regulation is one of them. Over the past decades, various countries (and therein often also regions or states) have introduced regulatory systems in LTC (Braithwaite *et al.*, 2007). As Pot and colleagues (2023) have shown, not much research has been done on how best regulation in LTC can be organized. In their scoping review, they found 31 empirical studies into the practice of regulating LTC over a period of 33 years (1989–2022). This is less than one scientific publication per year!

Whereas Evidence-Based Practice is common in current professional practice, evidence based regulation in LTC is far from that. In this context, the paper of Pot and colleagues offers a most valuable contribution by depicting the state of play of research up to now. It describes what topics were researched over those thirty years: care users' experiences in collecting intelligence, impact of standards, regulatory systems and strategies, differences and changes in inspection interventions, perception and style of inspectors, perception and attitude of inspectees, and reliability and validity of inspection outcomes (Pot *et al.*, 2023).

The question now is: what type of evidence is needed for effectively assuring, improving, and regulating quality in LTC to meet the current and

future challenges? Before this question can be addressed, one needs to discuss what the essence is of LTC and quality of LTC? Internationally, there is no clear-cut systemic definition or positioning of LTC (EC, 2021). It is often placed somewhere between health and social care. It has elements of and interconnections with both systems. Further, it relies not only on professionals but also to a large extent on informal carers. As such, LTC is best positioned in a context of integrated care (Beard *et al.*, 2016; Billings *et al.*, 2013).

This systemic positioning is a consequence of the characteristics of people with long-term needs, in particular people with dementia, and how these characteristics and needs are conceptualized. This conceptualization directs the objectives of LTC-service delivery and thereby the scope for quality assurance, improvement, and regulation.

As Beard and colleagues (2016) point out, traditional disease classifications miss the complexity of geriatric syndromes. The underlying multifaceted physiological changes, chronic diseases, and multimorbidity lead to multiple needs in functioning. It is the interaction of intrinsic capacities (i.e., "the composite of all the physical and mental (including psychosocial) capacities that an individual can draw on at any point in time" [p.5]) of people with the environment that determines whether they can live a life in dignity with basic rights and fundamental freedoms. This not only holds for older people. Similar principles are advocated in services for people with disabilities (Schalock and Verdugo, 2002).

So, LTC is to maximize and support human functioning for those with severe loss of capacities with a lifelong perspective on learning, growing, taking decisions, building and maintaining relationships, and to contribute to society (Pot, 2022).

According to this reasoning, cure and care are not the main aims of LTC services, but supporting people to live a "good" life. This implies dealing with the impairments and discomfort in their lives, as well as using available capabilities. Quality of care, thereby, serves quality of life. This, in turn, implies that quality is a moral and normative concept. It is dynamic and pluralistic, which differs according to the perspectives of the concerning people and their contexts (Koksma and Kremer, 2019). Professional LTC makes a specific contribution to a person's quality of life based on his/her choices and capabilities, his/her social network, and their social and physical context. The current focus on person-centered care reflects this approach (Beard *et al.*, 2016; EC, 2021; EC, 2022; Pot *et al.*, 2023; Pot, 2022).

When regulation is seen as one of the mechanisms to ensure, assure, and improve the contribution of LTC to people's quality of life, it has to take into consideration a particular conceptualization of quality, for instance, the conceptualization as depicted above. When quality is conceived as a "the appropriate delivery of a mutually agreed service or product" (Leichsenring *et al.*, 2013, p. 168), the question arises what these perspectives are and what the perspectives of regulators should be.

Various actors may hold various perspectives on what a good quality of life may be for a person and on what contributes to good quality (Nies and Leichsenring, 2018). In determining whether regulation is effective as a public value creating systemic intervention, the perspectives of services users (including their relatives), professionals, politicians, and the public are relevant (Leistikow, 2018). These perspectives may not only differ between the various actors but they may also even be in conflict with each other. For instance, safety measures to prevent falls of people with dementia or wandering outside the premises may run contrary to their rights for freedom of movement and preventing challenging behaviors.

Therefore, there are no universal norms of what is considered as "good quality," nor on what exactly regulators should focus on (Pot, 2022). There are more or less universal basic conditions for quality of life, such as rights, housing and material well-being, physical and mental well-being, social inclusion, interpersonal relationships, self-determination, and personal development. But these need to be attuned to personal idiosyncrasies and to context (Schalock and Verdugo, 2002).

Therefore, in order to evaluate the effectiveness of regulation, one needs to know how key players conceptualize good quality. Furthermore, the question should be answered how they see the purpose of regulation. Is the function of regulation to prevent negative outliers, and ensuring a basic level of quality, to assure publicly accountability, compliance to generic standards, or to facilitate learning and improving processes of LTC services? These different objectives may require different inspection strategies (Leistikow, 2018). They should go hand-in-hand with a deeper understanding of mechanisms of change and implementation strategies in order to have an impact on daily practice (Hovlid *et al.*, 2022; Pot *et al.*, 2023). When findings of inspection procedures cannot be transferred to effective interventions, regulation will not have any added public value. Therefore, in inspection procedures factors that are key for implementation are to be considered as well. Examples are leadership, organizational support, communication and coordination between disciplines, resources, skills of staff, available time, staff turnover, ongoing organizational changes, a learning climate, many projects running simultaneously, etc. (Groot Kormelinck *et al.*, 2021).

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However, regulation as such is also embedded in a particular context. It depends on the systemic positioning of LTC what the underlying values of its regulation are. Furthermore, it is relevant whether LTC is seen as a public, voluntary or private sector, for profit or not-for-profit. This may influence the answer to what the main purpose of regulation is in its particular systemic context: to ensure basic quality and safety, prevent exploitation or undesirable outliers, or to learn and improve quality of care and quality of life? Also the developmental state of the LTC system or dementia care system matters. There are large variations between countries, some of them having no system at all, while others have a well-developed and highly professionalized system (OECD, 2021; Spasova *et al.*, 2018; WHO, 2021). These different developmental states may lead to different regulation strategies and mechanisms.

The above conceptualization of quality of LTC requires new, innovative ways of regulation and inspection. There is a good point to make, as Pot *et al.* (2023) do, that LTC requires less standardized methods than for instance the health care sector. This implies, for instance, that in addition to "command and control regulation", more reflexive forms of regulation are needed (Pot *et al.*, 2023; Pot, 2022). Both types of regulation "set standards and criteria, collect information to assess whether the services comply with the criteria, and take action to meet criteria and make improvements" (Rutz, 2017, p. 14). The difference is that reflexive evaluation deals with uncertainty, involves multiple actors, and creates opportunities for learning; the latter also for inspectors. Criteria are open to adaptation. Prevention and creating options for improvement tend to be points of departure for this type of regulation (Rutz, 2017).

Research and theory development on LTC regulation need to incorporate these and other innovative regulation strategies. Up to now, theoretical program theories are seldomly explicated in studies on impacts of regulation. Program theories are useful for understanding which mechanisms bring about which outcomes under which conditions (Hovlid *et al.*, 2022). As regulation processes are layered (Pot *et al.*, 2023), research designs need to allow for complexity, multilayeredness, flexibility, and various contexts. Designs such as Realistic Evaluation (e.g. Hovlid *et al.*, 2022; Wodchis *et al.*, 2021), Drivers Diagram (see: Leistikow, 2018), and building Logic Models or Theories of Change in which the most relevant factors are explicated and researched (e.g. Wodchis *et al.*, 2020) meet these requirements.

Further, the potential for implementation needs to be incorporated, for instance by applying the so called "Consolidated Framework for Implementation Research." This is a comprehensive, "meta-theoretical framework," which allows researchers to identify the most relevant variables for interventions to be implemented (Groot Kormelinck *et al.*, 2021).

As the challenges for society, older people and informal carers are unprecedented, LTC will undergo massive changes. This will call for groundbreaking social innovations and new forms of professional, informal and societal support and care provision. Regulation of LTC requires full implementation in nations were LTC systems are underdeveloped and refinement and innovation in countries with more developed LTC systems. In both cases, regulation needs to be based on sound research, attuned to the challenges of regulation. Despite all uncertainties, one thing will be for sure: one scientific publication per year will not be sufficient to meet these challenges!

Conflict of interest

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