

We ask for regulations precisely to help us protect those whose rights are most likely to be violated. So, when our society struggles to meet the individual needs of our older adults living with the impact of chronic diseases such as dementia, when that happens... we put in rules and regulations to help us, so that when we are not watching, someone else is! This is what happens in many countries who have collective dwellings with assisted care, called, often times, long-term care homes. When something happens that is against the rules, we wonder... why weren't they watching? But what happens when we and our regulators get so caught up in the rules that we forget **why** we have regulators in the first place...or **what** we want them to be watching? Why is it that when something goes wrong, our instinct is to add yet another regulation to make sure it does not happen again? What if, as a result, things become regulated that might not need to be regulated? Well, when that happens... rights become violated.

For those societies who have not yet needed these watchdogs because the population is only beginning to grow old, is there anything that can be learned from others' experiences to make sure the path that is followed towards regulation keeps the values that are close to their heart and does not end up violating even the most basic human rights principles of dignity, fairness, equality, respect and autonomy?

While in developed countries, the fastest growing age group is 85 +, we must not forget that by 2050, 80% of the 2 billion older adults (65+) on this planet will live in the developing world. With this demographic change, and increased life expectancy, concern in the developing world will indeed need to shift from a focus on infectious disease to chronic disease management. And with the word "management" comes just that... "management" of diseases and their outcomes and indicators; the most prominent of these conditions being dementia. And this has impact on long-term

care, because most of the residents in these regulated homes have dementia and dementia impacts communication and cognition... making it hard for loved ones, clinicians and regulatory bodies to identify what they really want and whether the policies directed at their care respond to their needs to be protected and to maintain the best quality of life possible. We know something is amiss. Just read the papers.

Our perceptions of LTC homes have decreased and the portrayal of nursing homes in the media is consistently negative or, at best, neutral. Rarely, is it positive. So in countries which have significant regulation, the watchdog is being asked questions through the media. The alarm is raised and reported through the media – all media. Why aren't rules followed we are told? Why aren't people listened to? Why are family values not respected? Yet I was told recently that in the province where I live in Canada, there is one inspector for every 3 homes!

Regulations are now so elaborate that staff in homes spend more time reporting than taking care of residents. Employees live in fear that they will have forgotten to report an incident and that their home will be placed on a black list. One LTC administrator said to me that a resident holding hands with another could be construed as sexual misconduct and needed to be reported. Are these the kinds of gestures we wanted regulated? Some homes are not funded properly because the reporting is so onerous that they forego tabulating all events related to the residents' level of functioning just so they can get all their tasks done; even if, in a world of regulation, proper reporting leads to funding and more resources. The indicators and the outcomes that we tabulate are clinical; not quality of life or satisfaction. The regulations are designed to ensure safety. Yet, in many homes, not all, residents may not feel safe or may feel they are restricted and not in a home at all. Families might be ridden with guilt. Staff are overworked and find few opportunities to spend time with

residents, as they must focus on the multitude of care tasks. Residents with dementia might experience extensive changes in the people who care for them. They may experience staff that is not trained in how to interact with them. Often there is little or no flexibility in the rules. There are regulations for the number of baths you must take, when you should eat, and sometimes even what you should wear. Their home might look a bit like a hospital with staff wearing uniforms and everything is timed and costs are calculated to the number of adult incontinence material they buy or are allowed to use.

Is this why have put in rules and regulations? The 2013 Alzheimer report suggests that regulators have tended to, and I quote “focus on structures and processes rather than the essence of care quality – maintenance of personhood and wellbeing through a conducive physical and social care environment.”

Regulation is key to making sure that quality care is given and rights are respected. In countries where regulation is common, some feel it has become excessive and once again, will violate rights. In some parts of the world, regulation is so common, that individuals have no breathing room for quality of life in a highly risk-averse culture.

In other countries, mostly developing countries, the oncoming ageing of the population begs us to ask how it is possible to keep strong values while regulators become more commonplace. How can homes not turn into institutions?

Sebastiana Kalula, of ILC South Africa is quoted as saying “African people have traditionally enjoyed strong community and family support networks in which older people were well looked after in multigenerational, extended family households.” In developed countries, we have lost these values as we medicalized the approach and

turned our homes into long-term clinical homes. So how will African countries not fall to overregulation, yet maintain regulated bodies that preserve their values?

A paper published in 2017 reported that a country such as Malaysia is yet unprepared for its growing population who will need nursing home care. Residents, it is reported, are often housed in dorms with several residents to a room. This is unheard of in Canada as we know how such rooms are not conducive to quality of life and wellbeing, especially for people with dementia. But our populations suffer from social isolation. What can we learn from each other as collective dwellings are being considered worldwide? Some feel that developing countries may be running out of time. Even in countries where filial responsibility is strong and where care of older parents is not only culturally expected but sometimes mandated by law, it is clear that family carers may not have the financial capacity to take responsibility for their own, knowing that pensions, for instance, are unavailable. Furthermore, increased economic progress has led, in many circumstances, to the migration of the younger generation. So the need for collective dwellings to help the older population live with chronic conditions is becoming increasingly important. Redondo reports on the difficulties experienced by countries such as Argentina. This paper, dated 10 years ago, speaks of the need to offer institutional care for seniors to improve quality of care. Yet the models of home care management are seen to be repressive, there is insufficient training for staff and lack of understanding of these chronic conditions has led, in some cases, to elder abuse. So lack of or poor regulation, just as over regulation can violate some of the basic human rights of staying safe, the right to privacy, the freedom of thought and expression.

It is time we consider other solutions. For as Whittington (2014) says, “Why should we reasonably think that a doubling down on more of the same approach is likely to

yield a different, more salutary result now? Is it not time to seriously contemplate smarter, rather than just bigger regulation?”

We need to make regulations more meaningful, updated to today’s values, culturally sensitive and reporting needs to be cost effective and logical.

One approach is to make the results of regulation public – the shame or fame list. While this might lead to poorly performing homes being shut down eventually, are we sure performance is being measured with our values in mind? Will these lists discriminate those who perform “poorly” on hand holding from those who perform poorly on physical abuse? Some violations are clearly human rights based and should clearly be regulated. The question remains as to whether the indicators and the outcomes we currently have measure what is important. Clinical outcomes do not, as mentioned in the Alzheimer’s Report, capture how chronic conditions impact the person. For instance, many might consider being close to family more important than tabulating the number of baths taken that week. Cleanliness may be somewhat foregone to allow pets to be present in the home.

Regulators need to listen to the voiceless – make room to comment. The literature suggests that there exists systemic biases which render points of view hard to listen to. We must empower the voices and avoid ageist attitudes from others and from ourselves. We **can** ask that our fundamental values be respected, without fear of repercussions on ourselves or our family members. Bomhoff, 2017 says that “...policy makers fail to understand what is important to residents.” Investing in informal communication moments are seen as one way where the needs of residents, including cultural and spiritual ones are shared.

People are unique. It is time that we recognize what is fundamentally important to us and that we communicate that lives, even with advanced chronic disease, can continue to flourish, to find pleasure and wellbeing. That is why we need regulation – to make sure that someone is watching and making sure that happens when we cannot watch ourselves. Our advocacy groups can help by promoting these notions and by supporting new regulations that enforce proper values that are fundamental to us all. And finally, truths about what is fundamental to us all can be supported by a UN convention on the rights of the older person.