

# Listening to the voices of abused older people: should we classify system abuse?

Elder abuse is often the result of the organisation of health systems rather than the fault of individuals, argue **Yuliya Mysyuk and colleagues**. They call for system abuse to be acknowledged and addressed by incorporating older people's views when designing health services

Over the past few decades it has become clear that abuse of older people is a far reaching public health problem that affects the quality of life of people worldwide.<sup>1-4</sup> It disproportionately affects people with mental health problems, such as depression and dementia.<sup>1-5</sup> Currently, the most widely used definition comes from the World Health Organization: “a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.”<sup>6</sup> The definition focuses on a trusting relationship, includes acts of omission and commission, and is mostly interpreted as referring to interpersonal relationships.<sup>7</sup> However, scandals in the United Kingdom, such as at Mid Staffordshire<sup>8</sup> and Leas Cross,<sup>9</sup> indicate that the problem goes beyond interpersonal relationships.

For older people, care professionals are among the most important groups to identify and report abuse.<sup>10-11</sup> Despite this, only a small percentage of cases are reported by physicians<sup>10-12</sup> and elder abuse remains underreported.<sup>13-15</sup> It is therefore important that those involved in healthcare are in touch with the experiences and perceptions of elder abuse among victims. Yet, despite some exceptions<sup>16</sup> the voices of older people are relatively absent in debates about the typology of elder abuse, which is generally categorised as physical, emotional, financial, sexual, and neglect.<sup>1</sup>



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## SUMMARY POINTS

Older people often attribute neglect and abuse to organisational failures rather than to individuals

Such feelings do not fit current types of abuse

We propose adding system abuse—harm or distress to an older person that is caused by the organisation and resulting practices in our institutions—to the classifications of abuse

Older people's views should be sought when restructuring healthcare systems

To illustrate older people's views on abuse we draw on our qualitative studies on perspectives on elder abuse involving more than 100 people in the Netherlands—comprising experts, professionals, and, in particular, older people ( $\geq 65$  years).<sup>17-18</sup>

### An abusive system?

When we asked older people, “What do you think of when you hear the word abuse?” one of the issues recurrently highlighted was inadequate and insufficient care in institutions. One 69 year old woman who had received hospital treatment told us, “There is no respect for older

persons in all these institutions [nursing homes, home care organisations, and hospitals]. Older persons are abused in these institutions, abused by the healthcare system. It happens all the time; we can experience it every day. If you are old, then you are only a stick that lies in bed. They can only think: why is he still here and not dying? That is what we feel.”

Rather than blame individuals, older people identified institutional structures as responsible for their experience of abuse and neglect. Research in other countries, particularly in the United Kingdom and United States, and recurring scandals in care of older people,<sup>8-9-19</sup>

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► CQC produces guidance on using hidden cameras to identify abuse (*BMJ* 2015;350:h832)

confirm these findings and have led to proposals to reorient institutional abuse to pertain to structural arrangements instead of to individual behaviour or excesses.<sup>20 21</sup>

Older people also said that they felt disadvantaged or neglected as a result of changes in the financing and structuring of the Dutch healthcare system. One 82 year old man said, “In general, nursing homes, residential care facilities, and other institutions function particularly badly. And in my opinion the problem is in cuts and in restructuring that takes place.

These have an influence on the quality of care provided to older persons, which is insufficient.”

Studies among older people in countries as diverse as Australia, Ireland, Sweden, and the United States show a similar pattern.<sup>22-28</sup> The analogous restructuring of many healthcare systems worldwide through the introduction of mixed economies of care<sup>29-33</sup> and increasing specialisation seems to explain these parallels. Important aspects that were highlighted in these studies, also mirrored in the narratives of our participants, were excessive bureaucracy and a lack of clear responsibility in healthcare institutions. Even though these problems seem to be general, older persons believe that the way healthcare works, in terms of non-transparency, administration, and lack of overarching organisation is particularly harming them.<sup>21 24</sup> This may be because many older people may have multiple conditions, making them more likely to encounter the negative effects of the resulting fragmentation<sup>34</sup> and leaving them feeling vulnerable, powerless, and unable to approach someone because they cannot identify the person with prime responsibility.

Older people also felt that healthcare professionals were hostile towards them. For example, one 75 year old woman whose husband had been treated in a hospital and nursing home, said, “Often the staff of the hospitals or outpatient facilities are unfriendly. I experienced some hostility; it is quite strong in such environments.”

They sought the explanation for the hostility not just in ageism but also in inefficient planning by the care organisation, leading to a lack of supervision, knowledge, and training. They reasoned that this contributed to high levels of stress and work pressure that resulted in

negative attitudes towards older people—as if they were too demanding. Older people did not so much blame professionals for this, but as also detailed in studies from Ireland and the United States,<sup>26 27 35</sup> discussed how the care system was responsible for the behaviour shown by these professionals and how this particularly affected care for older people, who simply needed more time and patience.

Older people thought that healthcare institutions did not have a place for them and are unable, or unwilling, to take into account dif-

### The healthcare system and society at large are responsible for creating permissive circumstances in which abuse can occur

ficulties older people can encounter. These experiences seem related to negative attitudes towards older people in wider society but also show a tacit acceptance of the low priority given to

later life, as shown, for instance, by the 20% decrease in healthcare spending on people aged ≥65 in England over the past 10 years.<sup>36</sup>

This highlights, as others have also argued,<sup>27 37-39</sup> that the healthcare system and society at large are responsible for creating permissive circumstances in which abuse can occur. These permissive factors contribute to an implicit culture of abuse and neglect in which older people's care outcomes become compromised and self determination is ignored. For example, studies on pressures to speed up discharge have shown that they may inadvertently lead to higher mortality risks and have exposed the lack of involvement of older people in decisions to move to residential care.<sup>40-43</sup>

### Systemic nature of abuse

How can we acknowledge these views? We need to ensure that the voices of older people are heard and their experiences find resonance. One way to do this is to include what we call “system abuse” in the types of abuse. By system abuse we mean the organisation and resulting practices in our institutions that are (implicitly) abusive and cause harm or distress to an older person. This further extends WHO's definition to include a relationship between an individual and a system that finds its expression in the practices in our institutions.

Although the descriptions of abuse by older people might seem to resemble ageism, system abuse goes beyond Butler's<sup>44</sup> definition “as a process of systematic stereotyping of and discrimination against people because they are old.” System abuse includes measures that are

not necessarily ageist but disadvantage older people and eventually lead to actions that can be considered abusive or negligent—for example, digitalisation of healthcare and fragmentation of care leading to the exclusion or disempowerment of older people. By introducing system abuse into our definitions of elder abuse we can increase awareness of the, at times, implicit disadvantaged position, embedded hostility, and lack of respect older people experience as a result of structuring and financing.

One consequence of adopting the term system abuse is that the instigator of abuse is located in the system and not necessarily tied to the individual professional. This makes the responsibility for abusive acts less clear. Accountability for system abuse lies in the organisation and culture of care, and we should develop resources to integrate this liability. A multilevel approach<sup>45 46</sup> is needed in which the implications of people's behaviour are seen as set in organisational practices. We should monitor organisational incentives and ensure that they are changed if they are found to be associated with system abuse. This means that accountability is extended from the individual to singular institutions, to overarching sectors, and to local and national governments. We also need to develop definitions of injustice and wrongdoing based on older people's accounts, as has been done for sexual harassment and racism.<sup>47</sup>

Care of older people is facing rapid change, including increased numbers of patients, cultural shifts in expectations for later life, and retrenchment of welfare regimes. Healthcare systems, including the NHS,<sup>31</sup> are also dealing with big changes to their structure. By drawing explicit attention to the effects of (re)organisation on older people we can stop system abuse. We should make use of the opportunity offered by the transformational change that is needed in the NHS<sup>31</sup> and other healthcare systems by making older people participants in decision making and restructuring, instead of the subjects.<sup>48 49</sup> Analysis of the hidden disadvantages that any organisational changes may pose to our older patients will require further research into the experiences of older people. This way, the healthcare system, and society at large, will take a step closer to the lifeworlds of older people, opening up a debate about the organisation of healthcare and how we practise medicine.

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