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EDITORIAL

# Chronicity and primary care in times of pandemic☆

## Cronicidad y atención primaria en tiempos de pandemia

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In one of his daily appearances during the coronavirus pandemic state of emergency, the Director of the Coordination Centre for Health Alerts and Emergencies of the Ministry of Health, Fernando Simón, admitted that ''it is very hard to know what the real death rate from COVID-19 is; even though we have very good health statistics we will still not know the real death figure from this cause''.

If the attribution of mortality to coronavirus is unclear, what is even less clear are the primary or intermediate causes of death with their origin in complications in the majority of patients affected by chronic diseases, including neurological diseases. We could hazard a guess in saying that neurological patients have been a highly affected group, judging by the deaths by age groups. In mid-April the general fatality of infection by COVID-19 was 2.3%, and rose to 11% among those aged 70–79 years and 21.6% in those aged $\geq$ 80 years.

Basic epidemiological information has failed to produce case numbers and also hospitalisations and deaths by age groups, sex, social class, diseases and drug consumption for these diseases. In fact, many elderly people, apart from being too close together, were being treated, either rightly or wrongly, with psychotropic drugs and these drugs are associated with a higher probability of pneumonia. The increased risk of pneumonia or pneumonitis on the depression of immunity and other protective mechanisms (e.g. immunosuppressant agents and antipsychotics, some opioid analgesics, and proton pump inhibitors) leads to sedation which may increase the risk of aspiration on depression of pulmonary ventilation and promote the presence of atelectasis (e.g. opioids analgesic, anti-cholinergic drugs, psychotropic agents), or through a combination of these mechanisms.[1]

During the lockdown, primary care professionals reorganized to attend to mild cases at home and actively follow up people with greater vulnerability by phone, caring for their health and avoiding the complications that would require hospital admission. As well as treating mild cases, they have prevented the worsening by COVID-19 and other pathologies, which has protected peoples' health and prevented many hospital admissions, particularly for chronic patients.

Primary care has been responsible for periodic monitoring of patients whose condition was likely to worsen due to repercussions of isolation, non communication and immobility in chronic neurological patients.

Another no less important aspect has been putting into practice prophylactic measures to protect human relationships, maintain emotional stability and contain anxiety. In other words endeavour to sow calm to promote an environment of wellbeing. To do this it is essential to select the information and advice offered to patients, the content and tone of our communications, the way in which we interact to avoid ''infoxication'' (excessive information) to show how

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**Table 1** Assessment: Dementias and Alzheimer's disease, Parkinson's disease and stroke (mean stages of disease).

| Dementias and Alzheimer's disease | Parkinson's disease | Stroke |
|---|---|---|
| Has become extremely dependent on family members and care providers | Presents with greater motor impediment | Presents with greater functional impairment and disability |
| Degree of BADL (greater disability) | Degree of BADL (greater disability | Shows signs of cognitive impairment or changes with respect to their recent situation |
| Presents with greater difficulties with language | Motor complications (fluctuations or dyskinesias) | Control of most common vascular factors (HBP, tobacco consumption, diabetes and obesity) |
| Disorientation in own home | Non-motor complications: Urinary, cognitive impairment falls | If treatment with sustained-release oral anticoagulants has been established, control and review of them |
| Behavioural problems | Presents with problems swallowing | Changes to sleep |
| Changes to sleep | Changes to sleep | Problems relating to urinary continence have appeared |
| Sees or hears things that are not there | Suffers pain | Suffers pain |
| Shows dysfunctional patterns regarding feeding | Has received new treatments during lockdown period | Has lost habits relating to mobility |
| Has evacuation-related problems | Has lost routines relating to mobility prior to lockdown | Participation or socialisation activities have become impaired |
| Suffers pain | Psychosocial abilities have been affected | Has received new treatments during the lockdown period |
| Has difficulty walking | What type of aid or resources do they receive for their care? | What type of aid or resources do they receive for their care? |
| Has lost routines relating to mobility prior to lockdown | | |
| Has lost practices relating to cognitive stimulation prior to lockdown | | |
| Has received new treatments during lockdown period | | |
| What type of aid or resources do they receive for their care? | | |

time dedicated to the ''hypertheme'' should be strictly limited and to establish plans with tasks which take up attention and help to establish some type of sustainable normality.[2]

The impact of healthcare and more specifically primary care, on the most common and severe processes, such as dementias and stroke, are directly related to the disability and heavy dependency of these patients, which generate major social and health needs, for emotional care and support for patients, families and care-givers.

The current situation of the health crisis provoked by COVID-19 and the isolation measures imposed by the state of alarm decreed on 14th March led to the break-down of a series of routines and actions upon which the care of these patients was based, with their continued application being lost. These patients were not free from comorbidities or greater susceptibility to suffering from infections and as a result, right from the start of the pandemic they were classified as at risk patients and forced into strict home lockdown.

The protocol of the neurological patient who may currently be suffering the consequences of lockdown in the context of primary care, would be adults and the elderly over 65 years of age with sequelae of strokes or who suffered from Alzheimer's disease or any other type of dementia or Parkinson's disease, with different degrees of severity relating to the course of the disease.

Primary Care services must now face the effects of the reclusion of these patients and ensure the continuity of the whole range of care they receive. Care provided by the community is aimed at physiotherapy, at ensuring these patients maintain the highest level of autonomy possible.

An evaluation (Table 1) aimed at determining the functional, mental and social health situation of patients is therefore a way to detect possible changes or delays which occurred throughout lockdown and it is the necessary step before establishing new healthcare interventions, or the assignment of new resources and social-health resources and re-assessment.

The aim of the interventions would be to reverse disability and dependence to the levels prior to lockdown. Review and adjustment of pharmacological treatments, given the level of polymerization of these patients, will be a determining factor for the risk of side effects or interactions, with a possible effect on mobility, continence, sleep disorders, alertness, etc.

If changes are detected in the control of other diseases such as high blood pressure, diabetes mellitus, obesity etc., therapeutic endeavours will be increased until they are

controlled. If dysfunctional patterns are observed, relating to diet, such as malnutrition, dysphagia or other changes, the guideline will be to provide educational advice on diet or the prescription of appropriate nutritional supplements, both for energy and swallowing purposes. If the disability is related to mobility or carrying out activities of daily living (ADLs) with a high degree of dependency, greater aid will need to be assigned or home-based care, day centres, devices to aid mobility, etc.

When the pressure of current times falls, care will stop being monographic and the diaries of primary care professionals will revert to the common problems, rather than those derived from the lockdown. One of the relevant activities in these diaries should be home-based care, which is an irreplaceable activity to guarantee continuity of care and provide an early response to the many social and health requirements of these patients.

Managing the care of dependence in Spain should also take up a great deal of space in the diary of politicians at all administrative levels, from an increase in its expenditure to the functional and employment regulation for all citizens and those employed in this sector.[3]

A committed care situation for patients severely affected by infection has been the debate around which therapeutic resolution revolves and the possible limitation by age. News items have also circulated that could be included in the context of ''infoxication'' in parallel form to the pandemic. The Ethics Committee advisor to the Ministry of Health has been clear on this: elderly patients subjected to extreme scarcity of care resources, must be treated under the same conditions as the rest of the population, i.e.in keeping with the clinical criteria of each particular case. This implies that, eventually, and as the scarcity of basic means impedes the coverage of the requirements of the entire population, admission criteria will be applied to patients with serious symptoms in intensive care units and equally the application of mechanical ventilation in exactly the same conditions as for any other citizen. What is totally unacceptable is to rule out *ex ante* the access to these means to anyone who is above a certain age.[4]

Notwithstanding, in extraordinary circumstances, the ethics which guide decision-making differs from the ethics of care in normal situations. This is because the values and duties derived from the principle of justice putting collective health protection as the *prima facie* duty above all individual values become salient. This prevalence of the principle of distributive justice includes the ethical duty of planning and achieving maximization of the overall benefit, without compromising the protection of the most vulnerable people. This may require taking difficult decisions, such as equal distribution of goods or scarce resources, with patient selection being paradigmatic due to its moral difficulty (moral equality of all people) who will receive critical care when not everyone can be attended.

This prevalence of the duties of justice, in the most tragic of situations, must lead to the questioning of health autonomy since the patient (or their family or close relatives, where applicable) are not always able to participate in decisions concerning their health, their life and their death, and this is an immensely difficult issue upon which the whole of society, not only health professionals, must reflect. We are faced with the challenge of defending the values that are to be preserved without ignoring other duties, whenever possible, and this will not be easy, because the capacity for decision-making (healthcare autonomy) has been undermined. So too has the capacity for care by the professionals who will feel frustration at not being able to do what they consider would be best for their patient. Non-malfeasance also acquires a different dimension because faced with situations like the present one, where there is much uncertainty and insufficient proof (evidence), prudence, *lex artis* and an ethical vision must also be sustained. This entails doing the best for the individual patient, provided that this does not endanger the benefit of the greatest number of people.

Among the duties of not doing harm, issues such as care for critically ill patients come into play, together with decisions regarding appropriate therapy. These include end-of-life treatment decisions, orders not to begin CPR, removal of treatments considered to be futile, assessment of Advanced Directive documents and particularly care at the time of death, and they acquire enormous significance.[5]

Coming out of the crisis will affect relationships between professionals and patients, and the way in which they work (triages, risk selection, telemedicine, etc.). Considering what has been rehearsed during these last weeks of the state of alarm and social distancing, it is possible that there will be a cooling down of interpersonal relationships and a fall in personal and face-to-face encounters. Patient symptoms, signs and complaints may also be belittled or undervalued to delay home-care visits or face-to-face contact. We must be prepared for these situations because personalized attention, the emotiveness of contacts and the interpretation of emotions and gestures cannot always be replaced by the cold distance of digital communication.

In this pandemic, in this healthcare crisis, and in the subsequent financial crisis it will entail, essential challenges will continue to be that of avoiding the greatest number of deaths possible and ensuring that the social structures and fabric are not impaired. The exceptional measures of lockdown must not sow a seed of social deterioration or impairment of relationships, or care resources. Here the two essential pillars of the welfare state must be reinforced: on the one hand the conditions and criteria adopted to institutionalize chronic and/or elderly patients, because the poor conditions of the homes for the elderly have led to raised morbidity and mortality from COVID-19 infection. And on the other, the strengthening of the National Health System and Primary Care are essential, because primary care is the best qualified level for providing equal and preventative care to the whole population and for most effectively organizing coordination within the National Health System.

## Conflict of interests

The authors have no conflict of interests to declare.

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