



## EDITORIAL

## Patient experience with home respiratory therapies in Portugal: it is time to move forward



The number of patients needing home respiratory therapies (HRT), such as long-term oxygen therapy and/or home mechanical ventilation (HMV) in Portugal is increasing.<sup>1–3</sup> These therapies help individuals to improve function and live with greater quality of life; and assist them to remain at home, avoiding hospital emergencies, unscheduled consultations and hospitalizations.<sup>4</sup> Data from a recently published work confirms this increasing trend: in 2018, almost 80% of the HMV specialized centres were treating >30 new patients per year, currently treating >200 patients in total.<sup>5</sup> Moreover, the director of the National Program for Respiratory Diseases, based on the prescription database, showed that in 2017 the prevalence rose to a record of 80/100.000, very close to France, the country with the highest figures in Europe (C Bárbara 2019, personal communication, May 30th, Jornadas de Pneumologia CH Entre Douro e Vouga). An innovative national, patient-centred care home respiratory model was implemented in Portugal in 2014<sup>6</sup> and the major challenges are to create key performance indicators in order to maintain the access to HRT, national healthcare service sustainability and quality of care.

Patient experience is increasingly recognised as one of the three pillars of quality in healthcare together with clinical effectiveness and safety<sup>7</sup> and includes several aspects of health care delivery that patients value highly when seeking and receiving care, such as getting timely appointments, easy access to information, and good communication with healthcare providers.<sup>8</sup> An example of the importance of integrating the patient experience with healthcare delivery and quality evaluation is the inclusion for the first time of a dedicated chapter in the OECD (Organisation for Economic Co-operation and Development) and the European Commission report "Health at a Glance: Europe"<sup>9</sup> despite the recognition of patient-reported experience is still limited.<sup>9</sup>

In national health reference documents, the concept of patient experience is quite new. According to the Administrative Rule n.º194/2014 of September 30th, the existence of a monitoring system for the patient's experience was defined as one of the criterion needed for healthcare units be considered as reference centres (units providing healthcare, with verified technical knowledge on the

administration of high quality health care to patients in certain clinical situations). In 2015, an OECD report reviewing the quality of health care in Portugal, already concerned with capturing and reporting patient experience, identified the national mechanisms to collect patient feedback as being weak.<sup>10</sup> Nevertheless, the integration of patient experience seems to continue to be left out of relevant documents concerned with respiratory diseases management and specifically with HRT. This is a concern not restricted to Portugal. In fact, in a recent review conducted by the authors, from the 15 studies assessing the prescription of HRT, none have included the patient experience as an outcome.<sup>11</sup> Portugal was one of the countries with highest prevalence of HMV in Europe (9.3 per 100,000 people) according to 2001 Eurovent survey.<sup>2</sup> Considering this study took place almost 18 years ago, the current analysis of the data gathered by national HRT registers would be extremely useful to inform evidence-based healthcare policies.

Reference documents need to do more than advocate the importance of measuring patient experience. Healthcare providers, administrators and policy-makers need to know which tools are available for collecting patients' perceptions of healthcare provision and understand how they can be used to improve healthcare quality. The aforementioned review briefly described 14 patient-reported experience measures (PREMs).<sup>11</sup> Unfortunately, these PREMs were mostly generic and targeting diverse settings, and none was specific to assessing the patient experience with HRT. The translation/cultural adaptation of existent PREMs to the Portuguese population and/or the development of a specific PREM for patients on HRT should thus be a priority. These instruments could then be used to monitor patient experience and be integrated as quality indicators of HRT delivery. A number of key-points facilitating patient's treatment experience with HRT have already been identified as relevant for inclusion in a future PREM,<sup>11</sup> however, this knowledge comes mainly from international studies.<sup>12,13</sup> Studies exploring which topics are meaningful for Portuguese patients and carers are needed.

This letter shows that the contribution of Portugal to the research of patient experience and HRT provision has been

<https://doi.org/10.1016/j.pulmoe.2019.08.003>

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limited and raises further ways of moving forward in this emerging research area in the next few years. But most importantly, this letter underlines the need to go beyond Patient Reported Outcome Measures (PROMS) and create and integrate patient experience indicators — PREMs — into evaluation of the performance of healthcare services, including the national patient-centred care home respiratory model.

## Funding

C.J. has a post-doctoral grant (SFRH/BPD/115169/2016) funded by Fundação para a Ciência e a Tecnologia (FCT), co-financed by the European Social Fund (POCH) and Portuguese national funds from MCTES (Ministério da Ciência, Tecnologia e Ensino Superior).

## Declarations of interest

None.

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19 July 2019

Available online 26 September 2019