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JORNAL DA SOCIEDADE DAS CIÊNCIAS MÉDICAS DE LISBOA

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EDITORIAL, *by The Editorial Team*

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Teresa Carvalho [2]
Catarina Palma dos Reis [3]
Válter R. Fonseca [4]
Hugo Pinto Marques [5]

The Renaissance of a Bicentennial Medical Journal

We are immensely pleased to bring to reality the revitalization of one of the world's oldest medical journals. After a 21-year hiatus, this historic journal returns to serve a clinical and scientific world that has clearly changed.

In an era where new scientific journals emerge daily, with varying formats, quality, and impacts, it is legitimate to question why we would resurrect a journal like this. The answer lies in the desire to do different, to cover orphan topics, to serve healthcare professionals, researchers, and other groups that can benefit from this platform. And to facilitate access to a platform that can positively provoke the community of all those who contribute to the health of populations.

We aim not just to honor our heritage, but rather be a sign and a contribution to the advancement and innovation in medicine in its multiple facets.

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In this new life cycle, we are broadening our focus to include not only physicians but also other healthcare professionals and new emerging areas with implications for health. Medicine is increasingly an interdisciplinary activity, and we recognize the importance of integrating the diverse disciplines that contribute to this new model of care delivery. Thus, in addition to topics of clinical practice and research, our journal will place special emphasis on medical education, health technologies, interdisciplinary care, other healthcare professionals, and global health. It will also be our priority to become a privileged place for publication and consultation by our university students, thereby helping to disseminate their protocols and quality results.

Publishing in an open-access format, without publication fees and in English, is also a sign of our commitment to favoring a global but inclusive vision, while never losing the commitment to rigor and quality. We are committed to ensuring that each edition of our journal reflects the highest standards of scientific and ethical rigor, regardless of study design and publication format.

We invite all healthcare professionals, researchers, academics, engineers, and students to contribute their work and visions, sharing knowledge that can inspire and transform people's health.

We thank the two oldest medical schools in Lisbon for the trust placed in us, as they now consider the JSCML their scientific publication.

Together, we will continue to honor our historical legacy while shaping the future of medicine.

With enthusiasm,
The Editorial Team

> *We aim not just to honor our heritage, but rather be a sign and a contribution to the advancement and innovation in medicine in its multiple facets.*

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JORNAL DA SOCIEDADE DAS CIÊNCIAS MÉDICAS DE LISBOA

EDITORIAL

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Portugal has witnessed remarkable advancements in medical care provision since the establishment of the National Health Service (SNS) in 1979, leading to improved quality of life and increased longevity.

This progress can be attributed to a combination of several factors, including the education and training of skilled professionals, effective public health strategies, accessible primary healthcare, and advanced specialized hospital medicine. These components have facilitated the swift integration of international scientific advancements into our healthcare system. However, this commendable progress now faces critical sustainability challenges. Issues such as financial viability and the retention of skilled professionals within the SNS, exacerbated by unsatisfactory remuneration, threaten its stability. Additionally, heightened competition for talent from private healthcare institutions within Portugal and abroad compounds these challenges.

The Sociedade das Ciências Médicas de Lisboa (SCML), is relaunching its Journal with a series of papers analyzing the healthcare situation in Portugal and globally. In fact, the inaugural paper in the first edition in 1835, characterized the state of medical and surgical care in Portugal, highlighting the importance of delivering care to the population.

Effectively managing the healthcare needs of the population, motivating healthcare professionals, and ensuring the economic viability of the SNS are among the pivotal challenges of the early 21st century.

As the official journal of the Sociedade das Ciências Médicas de Lisboa, endorsed by the two public Lisbon Medical Schools, it has the potential to become a powerhouse for strategic academic medical discourse and a platform for publishing student-driven research projects, particularly those stemming from master's theses.

At the core of medical advancement is the presence of training and research centres that invigorate the entire healthcare ecosystem, fostering progress, specialization, and motivation among all stakeholders. The establishment of Clinical Academic Centres (CACs) within University Hospitals, in collaboration with medical schools and research institutes, plays a pivotal role in this regard. These centres not only provide training to medical students and residents but also offer continuous postgraduate education to healthcare professionals nationwide. Furthermore, they serve as hubs for medical research, fostering collaboration between clinicians, clinician-scientists, and non-clinical researchers, thereby integrating scientific discoveries into clinical practice, and addressing patients' needs through clinical trials.

This integration of medical training and clinical practice with scientific research has become a cornerstone of modern healthcare. Future healthcare professionals must be immersed in the culture of the scientific method, encouraged to question and explore the complexities of medical science, and adapt to emerging technologies such as artificial intelligence and advanced imaging techniques.

The establishment of differentiated career paths within health units associated with CACs is essential to incentivize professionals to engage in clinical, training, and research activities. These careers should allow for a balanced allocation of time between SNS clinical duties and academic pursuits, with rewards tied to clinical excellence, educational contributions, and scientific output. Such collaborative efforts between healthcare providers, Medical Schools, and Research Institutes, under the framework of CACs, epitomize the ideal environment for professional development and medical research advancement.

This journal can serve as a proactive tool in the scenario described above. As the official journal of the Sociedade das Ciências Médicas de Lisboa, endorsed by the two public Lisbon Medical Schools, it has the potential to become a powerhouse for strategic academic medical discourse and a platform for publishing student-driven research projects, particularly those stemming from master's theses.

As the Deans of the two medical schools, we are very proud of being part of this collaborative effort that promotes education and research, increases knowledge and in the end, improves population's care, health and wellbeing.

VIEWPOINT

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JORNAL DA SOCIEDADE DAS CIÊNCIAS MÉDICAS DE LISBOA

Quality of Care: an imperative for current healthcare systems

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ABSTRACT: Despite unprecedent health achievements in the last centuries, the total number of annual deaths globally will grow in the decades ahead, because of population growth and population ageing, along with persisting inequalities. It is imperative to double down on efforts to go beyond classic public health measures. Current evidence shows that health care is often inadequate, and poor-quality across conditions and countries, with the most vulnerable populations faring the worst. The United Nations Agenda 2030 set Universal Health Coverage (UHC) as sustainable development target. This transformative shift in health policy design and implementation places quality of care at the heart of the global health agenda. Indeed, health improvements can remain elusive unless those services are of sufficient quality to be effective. Transformation of health care will require an unprecedented commitment to quality improvement, but it will not be possible to continue using the methods and approaches of the past. With the global momentum of UHC as a backdrop, combined with the previous decades of work on healthcare quality worldwide, the time is ripe for advancing high-quality healthcare systems that optimize health care in a given context by consistently delivering care that improves or maintains health outcomes, by being valued and trusted by all people, and by responding to changing population needs. Quality of care must be a political priority. Quality of care policies need to evolve by prioritizing UHC, investing in high-quality systems, engaging in continuous learning and improvement, adopting tracer indicators to reorient health systems towards outcomes that matter to people, and leveraging digital tools for a data-driven culture and reducing health inequalities.

KEY WORDS: Health systems, Quality of Care, Universal Health Coverage

From the inception of the Jornal das Ciências Médicas de Lisboa nearly two centuries ago, numerous barriers have been removed, leading to significant advancements in medical science, healthcare, and overall population health. Global life expectancy rose from 46.5 years in 1950 to around 73 years in 2019 and is projected to reach 77 years by 2048[(1)]. This improvement reflects the shift from high infant mortality and infectious diseases to chronic non-communicable diseases due to better hygiene, sanitation, antibiotics, vaccines, and global vaccination efforts. Additionally, changes in economic, social, and cultural aspects have altered risk factor profiles, including behavior, metabolism, and environment-related factors. In addition, economic, social, and cultural factors,

have led to significant changes in the profiles of risk factors – including behaviour-related factors such as smoking, harmful alcohol use, physical activity and diet, metabolic-related factors such as obesity and hypertension, and environment-related factors such as air pollution, water, and sanitation.

Despite these unprecedent achievements, the total number of annual deaths will grow in the decades ahead, because of population growth and population ageing. However, mortality is only part of the picture of population health. As survival rates continue to improve across nearly all causes of deaths, non-fatal outcomes become more prevalent.

Additionally, striking inequalities persist. The most vulnerable groups continue to face an elevated risk of dying and disability from avoidable communicable, maternal, perinatal and malnutrition conditions. Along with these existing challenges, the emerging noncommunicable diseases associated with unhealthy lifestyles, environmental hazards and an ageing population creates an unsustainable burden for healthcare systems.

It is imperative to double down on efforts to go beyond classic public health measures. Current evidence shows that health care is often inadequate, and of poor-quality across conditions and countries, with the most vulnerable populations faring the worst. Poor quality is estimated to account for up to 58% of preventable deaths in low- and middle-income countries, exceeding the burden of disease attributable to a lack of access to healthcare[2]. Overall, poor-quality care can lead to adverse outcomes, including unnecessary health-related suffering, persistent symptoms, loss of function, and a lack of trust and confidence in health systems[3]. Substandard care also exerts a substantial economic impact and side-effects such as catastrophic expenditures and increases in the cost of expanding health coverage[4].

However, it took until 2015 to place quality of care at the centre of the global health policy agenda. While quality of care is widely – and somehow intuitively – recognized as a key component of healthcare delivery, it has not been a consistent focus in practice.

The United Nations Agenda 2030 set Universal Health Coverage (UHC) as a sustainable development target, including financial risk protection, access to quality essential healthcare services and access to safe, effective, quality, and affordable essential medicines and vaccines for all[5]. This means all people and communities should have access to the high-quality health services they need – promotive, preventive, curative, rehabilitative, or palliative – without facing financial hardship[6]. This has been a remarkable gamechanger in the way health policies are designed and implemented. From "crude coverage", with a solely focus on access, to "effective coverage" which takes into account the need for, the use of, and the quality of healthcare services[7]. Health improvements can remain elusive unless those services are of sufficient quality to be effective.

Traditionally, quality of care has been defined in the intimacy of the physician-patient relationship and assumed as a complex and multifaceted concept with potentially varying definitions across contexts, disciplinary paradigms and levels of analysis[8]. While Donabedian stated that it seems likely that there will never be a single comprehensive criterion by which to measure the quality of patient care, he recognized that quality of care may have a wider dimension[9]. In 1966, he suggested quality of care may be almost anything being a reflection of values and goals in the medical care system and in the larger society of which it is a part. This paved the way for an intersection between public health and clinical medicine[10].

More recently, it is accepted that achieving "the highest attainable standard of health" – a right enshrined in the World Health Organization's constitution – depends not on public health or clinical medicine alone, but on "where the twain shall meet"[11]. It is crucial to view quality of care not just as a point estimate that applies during one clinical encounter. Rather, quality of care is appropriately considered essentially as a longitudinal concept, a systems property affected by decisions occurring at all levels of a healthcare system. Thus, optimizing the system design at all levels should be a priority[12]. And, unless proper measures, oversight mechanisms, patient engagement, and health literacy are built into systems, it is possible that UHC efforts will provide access to poor-quality, eventually harmful care[13].

Transformation of health care will require an unprecedented commitment to quality improvement, but it will not be possible to continue using the methods and approaches of the past. To drive positive transformation and achieve UHC, it is imperative to establish quality of care as a systemic organising principle. This principle should apply not only to individual healthcare services, but also to entire health systems, fostering a beneficial intersection between individual needs and societal demands[14].

Since the establishment of the 2030 Agenda for Sustainable Development healthcare systems are in the turmoil of growing challenges and demanding aims (Figure 1).

The term "permacrisis" is increasingly used to describe the convergence of multiple crises straining health systems, such as the pressing effects of the COVID-19 pandemic, wars and conflict, natural disasters and the escalating health-related consequences of climate change. The pandemic has exposed pre-existing vulnerabilities in health systems while also spotlighting innovative solutions that could enhance healthcare delivery in the post-COVID-19 era[15]. Additionally, health systems and social care sectors are contending with exhausted frontline staff, depleted budgets, and a backlog of patients awaiting treatment. While the full legacy of this prolonged stress is not yet fully understood, it is clear that the situation demands more than short-term fixes. Effective responses require governance foresight, characterized by creativity, innovation, and collaboration across all sectors.

If quality is indeed a systems property affected by decisions occurring at all levels of a health care system, optimizing the system design at all levels should be a priority. While much conceptual work has applied systems principles to the health care field, most interventions to date have focused on increasing access, improving training, instituting financial incentives, and a few other targeted efforts. By neglecting to take a holistic perspective, such interventions fail to address the underlying issue behind poor quality: poorly structured organizational contexts and process inefficiencies that interact with each other and at multiple levels[16].

A 2018 review of primary care quality found that, globally, 72% of strategies targeted the micro level. Although interventions aimed directly at facilities can be motivational and promote local commitment to quality of care, people tend to revert to entrenched ways of doing things, especially when surrounding systems do not support transformation[17]. In a seminal paper published by Kruk and colleagues propose that a transformative quality improvement agenda is based on the recognition that health systems are complex adaptive systems[18]. This approach emphasises macro-level reforms. Macro-level strategies are best able to directly tackle the social, political, economic, and organisational structures that shape a health system. System-wide improvements in quality of care will require effort from providers, health system administrators, and communities, but they begin with a political commitment from heads of state and ministers[19].

With the global momentum of the UHC as a backdrop, combined with the previous decades of work on health care quality worldwide, the time is ripe for advancing high-quality healthcare systems as the ones that optimize health care in a given context by consistently delivering care that improves or maintains health outcomes, by being valued and trusted by all people, and by responding to changing population needs[20].

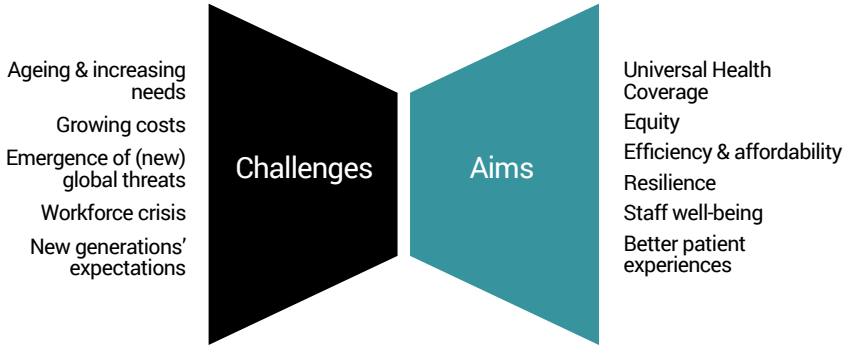

Fig 1. Healthcare systems in the turmoil of increasing challenges and demanding aims

Overall, the current evidence and global health policy trends highlight the need for underpinning quality of care as a driving force for the decisive transformation of healthcare systems[21]. A growing number of countries in the WHO European Region are making investments into high-quality health systems. These countries show the ability to understand the root causes of poor quality and to implement actions to address these causes. They develop quality care policies and strategies that encourage systemwide efforts for improvement and consequently make the necessary investments into favorable health system foundations for quality including: governance and leadership, intersectoral collaboration, health workforce, financing, medicines, medical products and technologies, infrastructure, health information systems, community engagement and participation, health promotion and disease prevention and the research and learning capacity of organizations.

While many efforts are underway to strengthen quality of care and patient safety at the national level, data collected from the WHO European Region Member States highlighted that reporting of the quality of care dimensions remain highly heterogeneous across the European region. Data fragmentation and knowledge gaps have a profound impact on the decision-making process and health outcomes. Therefore, the adoption of agreed-upon metrics and a common vision for quality of care at the regional level underpins a data-driven transformation of healthcare systems.

Quality of care policies need to evolve by prioritizing UHC, investing in high-quality systems, engaging in continuous learning and improvement, adopting tracer indicators to reorient health systems towards outcomes that matter to people, and leveraging digital tools for a data-driven culture and in reducing health inequalities.

Quality of care must be a political priority and an important contributor to UHC, population health and health systems strengthening. To achieve a positive, effective, and sustainable transformation of health systems, there must be a concerted and intensified focus on several key areas. These include developing and implementing robust national quality policies and strategies; preventing avoidable harm through a culture of continuous learning; ensuring good governance; building a health workforce tailored to meet current needs; aligning financial incentives with health service delivery goals; providing accessible, high-quality medicines; focusing on outcomes that matter most to people; developing a robust digital infrastructure; fostering innovation; and enhancing patient and community involvement in health decision-making and service evaluation.

DISCLAIMER

The authors affiliated with the World Health Organization (WHO) are alone responsible for the views expressed in this publication, and they do not necessarily represent the decisions or policies of the WHO.

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JORNAL DA SOCIEDADE DAS CIÊNCIAS MÉDICAS DE LISBOA

Military Surgeons and the Teaching of Surgery in the Portuguese World – 1773-1910

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ABSTRACT: In Portugal, including several overseas territories, in particular Portuguese America, the Military Institution and the Military Surgeons actively contributed to the teaching of surgery and to the care of the most peripheral and vulnerable populations. This reality, whether through the rudimentary teaching of Anatomy and Surgery in the Military Hospitals, or through the Anatomy and Surgery Classes, and later in the contribution to the Royal Schools of Surgery and Medical-Surgical Schools formation, cannot be forgotten.

KEY WORDS: Portugal, Military Institution, Military Surgeons, Surgery Education

INTRODUCTION

Traditionally, the figure of Teodoro Ferreira de Aguiar is evoked for his particular and presumed intervention in the creation of the Royal Schools of Surgery of Lisbon and Porto. However, it would be too simplistic to consider him an isolated actor and to ignore the institutional and other military surgeons' efforts since the third quarter of the eighteenth century.

I – The Last Quarter of the Eighteenth Century

Until the end of the eighteenth century (and even in the first decade of the nineteenth century), the training path of surgeons varied widely. Many pursued simple learning methods without undergoing examinations by the competent authorities, including the Chief Surgeon of the Kingdom, the University of Coimbra (1772-1782) or the Junta do Protomedicato (1782-1809). This process was complex, often involving overlapping jurisdictions, insufficient resources, and was not free from corruption[1]. Some degree of solid training was available in civil environments, notably in the Royal Hospitals of S. José and Misericórdia do Porto, but also in those of the Misericórdias of Évora and Setúbal[2].

However, due to the scarcity of practitioners, this requirement was often ignored (3), and even rarer was their submission to assessment by civilian authorities[1,4].

To try to improve the level of surgeons admitted to the Corps, the Military Institution created Anatomy and Surgery Classes in Almeida, Elvas, Tavira and Chaves, between 1773 and 1789. The establishment of the latter was particularly urged by Manuel José Leitão, Surgeon of the Royal House and later Major Surgeon of the Cavalry Regiment of Chaves. It should be noted that Elvas and Chaves could even, in addition to student soldiers, receive civilian students who, wishing to continue or join the ranks, had

priority in admission to vacancies of Surgeon Major in the Regiments of these Provinces[3,5]. Manuel José Leitão published a Treatise on Anatomy.

During this period, surgery and anatomy were taught in other Military Hospitals, such as the Navy Hospital and, in Portuguese America, in Rio de Janeiro and Goiás, among others[6]. As an example, Teodoro Ferreira de Aguiar, born in Rio de Janeiro, in 1800, 3 years after returning from France and Leiden, identified himself as Chief Surgeon and Professor of Surgery at the Navy Hospital in an application for the position of Surgeon Major and Royal Professor of Surgery at the Military Hospital of his hometown[7].

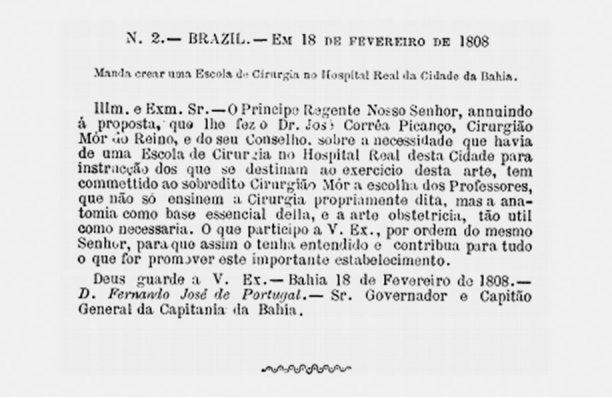
Several of the most categorized Military Surgeons were Deputies or Commissioners of the Chief Surgeon of the Kingdom or of the Board of Protomedicato, according to their validity, in the evaluation of credentials or examining candidates for the practice of surgery, the office of bleeder, algebraist ("endireita"), etc.

II – The First Two Decades of the Nineteenth Century

In addition to the efforts of personalities such as Bernardo José de Abrantes e Castro, Inspector of Military Hospitals, regarding the observance of the assessment of credentials and knowledge by the Chief Surgeon of the Army, he and Ferreira de Aguiar, at the time already "Cirurgião Mór da Armada Real e dos Exércitos", drafted, at the request of António de Araújo de Azevedo, a Regulation for Military Hospitals[8]. Approved in Salvaterra de Magos on March 27, 1805, it provided, in Title II, article XIX, the obligation to teach medicine and surgery, because "It is not possible to separate Medicine from Surgery; and the Military Hospitals should be from today to the future true Schools of Surgical Medicine (...)".

In 1807, José Correia Picanço, who had been Chief Surgeon of the Kingdom since 1799, went to Brazil (an official page - Memórias da Administração Pública do Brasil - also mentions him as having been Chief Surgeon of the Armies, a quality that could not be confirmed, in particular due to the absence of references in the Military Historical Archive). Born in Pernambuco, probably the son of a "barber-surgeon", he was appointed, in 1766, at the age of 21, surgeon of the "Corpo Avulso de Oficiais de Ordenança dos Entrados e Reformados"[9]. Recommended for his work, he managed to go to Lisbon where he enrolled in the Surgery Course at the Hospital de S. José, becoming a disciple of Manuel Constâncio[9]. After his graduation, he was appointed by his master to go abroad for training, a decision he accepted, as can be seen by the birthplace of his eldest son (Paris)[9,10].

He was a demonstrator of Anatomy and Surgical Operations at the University of Coimbra between 1772 and 1778 and then lecturer between 1779 and 1790, after a doctorate at a non-consensual date and place (Paris? Montpellier?). Enjoying great prestige, being Surgeon of the Royal House, knighted and awarded with the habit of the Order of Christ, and Member of the Board of Protomedicato, he is clearly assumed as the mentor, together with the Prince Regent, in the creation of the Escola Cirúrgica da Baía (the oldest University in Brazil) by the Decree of 18 February 1808, which is reproduced below[11].



N. 2.— BRAZIL.— Em 18 de fevereiro de 1808

Manda crear uma Escola de Cirurgia no Hospital Real da Cidade da Bahia.

Illm. e Exm. Sr.— O Principe Regente Nosso Senhor, annuindo á proposta, que lhe fez o Dr. José Correa Picanço, Cirurgião Mór do Reino, e do seu Conselho, sobre a necessidade que havia de uma Escola de Cirurgia no Hospital Real desta Cidade para instrucção dos que se destinam ao exercicio desta arte, tem commettido ao sobredito Cirurgião Mór a escolha dos Professores, que não só ensinem a Cirurgia propriamente dita, mas a anatomia como base essencial della, e a arte obstetricia, tão util como necessaria. O que participo a V. Ex., por ordem do mesmo Senhor, para que assim o tenha entendido e contribua para tudo o que for promover este importante estabelecimento.

Deus guarde a V. Ex.— Bahia 18 de Fevereiro de 1808.— *D. Fernando José de Portugal.*— Sr. Governador e Capitão General da Capitania da Bahia.

Fig 1. The Decree of Creation of the School of Surgery of the Bay, on February 18, 1808. Credit – Colleção das Leis do Brazil (Rio de Janeiro: Imprensa Nacional, 1808, Parte I), 2.

Current bibliography and historiography have also attribute to him the founding of the "Aula de Anatomia e Cirurgia" or "Escola Anatómica, Cirúrgica e Médica", of Rio de Janeiro, in the Military Hospital of that city, a narrative that is not possible to definitively confirm. With the initial designation of Cadeira de Anatomia (April 2, 1808), its creation appears to be the result of a collective initiative with His Royal Highness support (in addition to Picanço, also from Frei Custódio de Campos, Cirurgião Mor "dos Exércitos e Armadas Reaes", Joaquim da Rocha Mazarém and others)[12].

As for Teodoro Ferreira de Aguiar, he also accompanied the Royal Family in the transfer to Rio de Janeiro, supposedly being in charge[3], on April 2, 1808, of teaching Anatomy at the Military Hospital of that city and, on October 12 of the same year, in charge of teaching Ligatures, Surgery Operations and Parturia-

tion which he would have continued until 1813. These assertions are refuted by consultation with the Collecção de Leis do Brazil[13], by which we were able to verify that the Decrees of 2 April and 12 October 1808 refer to Joaquim da Rocha Mazarém as Anatomy Teacher of the Military Hospital and, in the latter, additionally stipulating the obligation to teach Ligatures and Parturiation. Mazarém began his training in the Anatomy and Surgery Class of the Military Hospital of Chaves, later moving on to the Royal Navy and, as we will see, he will also play a prominent role in the teaching of obstetrics in Lisbon.

Regarding Continental Portugal, in 1816, we have news of the intention of the Enfermeiro Mor of the Hospital de S. José, António da Câmara, to reform the facilities and the teaching of surgery at his School[3]. On the other hand, Beresford, at the end of the war, promoted the internship of several Assistants of Surgery of the Army Corps not yet approved in the School of Surgery of that hospital[14]. The desideratum of these personalities converged with or was a reflection, in the case of the Chief Marshal, of the content of the Charter of June 14, 1816. In this document, D. João VI ordered the observance of the Regulation of Military Hospitals of 1805 (to the detriment of the 1813 one promoted by Beresford), with some changes, and mandated the creation of a Military Medical School at the Hospital of S. José.

III – The Twenties of the 19th Century

In 1822, with the aim of encouraging a modern and scientific approach to medicine (in the broad sense), as well as promoting the method of "mutual teaching"[15], pharmacology, public health, among other aspects, a group of doctors, surgeons and pharmacists from the Military Hospitals, meeting in the Convent of S. Francisco da Cidade, created the foundations of the Society of Medical Sciences of Lisbon, later extending the invitation to a greater number of members. Having decided the 1rst December to be the date to make the official "installation", elections were held on 26th November for the Board of Directors and Committees[16]. For reasons of the Elected President's health, Francisco Soares Franco was quickly chosen as President of the Society, to whom Abrantes e Castro, former Inspector of Military Hospitals and an old rival, will make the report of the deputation, which he headed, sent to D. João VI (who received them at the Palace of Bemposta). As has been pointed out, among the founders of the society there were numerous members who belonged or had belonged to the military institution, which was the case for all the doctors and surgeons of that deputation. As a curiosity, it is noted that Francisco Soares Franco became president of the Army Health Council between 1837 and 1841. The first phase of the Society was short-lived, since, with the absolutist movement of 1823, its sessions were interrupted from May 1823, and the Society suspended in December. It was only reinstated in 1835. By 1866, there were five Presidents of the Society who were or had been military physicians or surgeons[5].

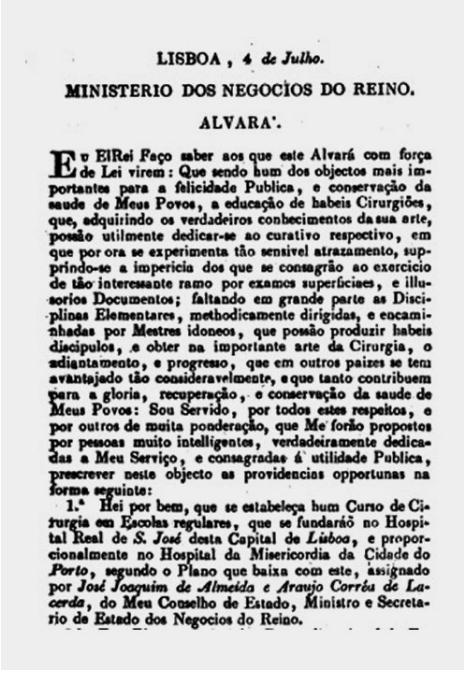
A project already cherished by several personalities (the Enfermeiros Mores of the Hospital de S. José, for example, as already mentioned) and the Crown, the foundation of the Royal Surgical Schools of Lisbon and Porto resulted from a collective effort, including military surgeons such as Teodoro Ferreira de Aguiar (also a PhD in Medicine), who played a particularly important role, Jacinto José Vieira, Joaquim da Rocha Mazarém, António Pedro Cardoso, Vicente José de Carvalho, Joaquim Inácio Valente and António de Lima Leitão (also a Medicine Doctorate).

Although some attribute its foundation to Jacinto José Vieira[18], the future Chief Surgeon of the Kingdom[10], most of the bibliography and historiography presents a version of the issue based on tradition, which is perpetuated, especially based on the work A Régia Escola de Cirurgia (The Royal School of Surgery), by Professor Augusto Silva Carvalho[19]. Viera Reis was not an exception and transcribes some excerpts from it. On the subject, Silva Carvalho[19] says:

> *"It is well known that Teodoro Ferreira de Aguiar managed to have one of the tobacco contractors released, taking advantage of the high esteem in which he was held by D. João VI, a favor that the beneficiary tried to pay with a large sum that that meritorious doctor refused, asking in exchange that it be used to subsidize two schools of Surgery in Lisbon and Pôrto, not by a one-time gift, but by an annual subsidy payable by all the contractors of that manufacturing monopoly."*

With this commitment (most likely coming from José Ferreira Pinto Basto, according to our investigations), Teodoro planned the course of the new schools and drew up the budget for their expenditure and revenues, as can be seen "clearly" from a letter, addressed to the Minister and Secretary of State for Kingdom Affairs, signed by him and dated 26 May 1825[19]. Although Lima

Leitão stated that the Regulation had been drawn up by Joaquim da Rocha Mazarém, Silva Carvalho maintains his conviction regarding Teodoro Ferreira de Aguiar. His explanation for this lack of definition stems from the apparent modesty of Teodoro, who even suggested that the first Director should be Jacinto José Vieira[19]. The Charter for the Creation of the Royal Schools of Surgery (25 June 1825) and its Regulation are published in the Gazeta de Lisboa of 4 July 1825[20]. In the first, it is clear that the initiative resulted from the intervention of several personalities: D. João VI, in the Charter of its creation, speaks of a project that was brought to his consideration by "very intelligent people"[20]. The inaugural speech, delivered in the presence of King João VI and the Infantas, on 27 September 1825, by Francisco de Assis Leite, one of the teachers, is silent on the specific role of Ferreira de Aguiar or others[21].



LISBOA, 4 de Julho.

MINISTERIO DOS NEGOCIOS DO REINO.

ALVARA'.

Eu ElRei Faço saber aos que este Alvará com força de Lei virem: Que sendo hum dos objectos mais importantes para a felicidade Publica, e conservação da saude de Meus Povos, a educação de habeis Cirurgiões, que, adquirindo os verdadeiros conhecimentos da sua arte, possão utilmente dedicar-se ao curativo respectivo, em que por ora se experimenta tão sensivel atrazamento, supprindo-se a impericia dos que se consagrão ao exercicio de tão interessante ramo por exames superficiaes, e illusorios Documentos; faltando em grande parte as Disciplinas Elementares, methodicamente dirigidas, e encaminhadas por Mestres idoneos, que possão produzir habeis discipulos, e obter na importante arte da Cirurgia, o adiantamento, e progresso, que em outros paizes se tem avantajado tão consideravelmente, e que tanto contribuem para a gloria, recuperação, e conservação da saude de Meus Povos: Sou Servido, por todos estes respeitos, e por outros de muita ponderação, que Me forão propostos por pessoas muito intelligentes, verdadeiramente dedicadas a Meu Serviço, e consagradas á utilidade Publica, prescrever neste objecto as providencias opportunas na forma seguinte:

1.° Hei por bem, que se estabeleça hum Curso de Cirurgia em Escolas regulares, que se fundarão no Hospital Real de *S. José* desta Capital de *Lisboa*, e proporcionalmente no Hospital da Misericordia da Cidade do *Porto*, segundo o Plano que baixa com este, assignado por *José Joaquim de Almeida e Araujo Corrêa de Lacerda*, do Meu Conselho de Estado, Ministro e Secretario de Estado dos Negocios do Reino.

Fig 2. Excerpt from the Charter for the Creation of the Royal Schools of Surgery (June 25, 1825). *Gazeta de Lisboa,* Suplemento ao nº 154, de 4 de Julho de 1825, 641.

In Porto, we also found the participation of several military "facultativos", such the already mentioned Vicente José de Carvalho, surgeon and first Professor of Anatomy, born in Setúbal and who graduated from the Hospital de S. José, and Joaquim Inácio Valente, born in Lisbon. The Inaugural Session took place on November 25, 1825, and Bernardo Campeão, first Director of the School and 1st Physician of the Military Hospital of Porto, delivered the "Inaugural Oration"[22]. Salustiniano Arnaud, also a physician attached to the military institution (as well as a military engineer), served as Director for some time during the Civil War[3,22].

IV- Medical-Surgical Schools

In 1836, by Decree of 29 December, the Medical-Surgical Schools of Lisbon and Porto were created, succeeding the respective Royal Schools of Surgery. It should be noted that it was only in 1866 that the same rights and prerogatives were recognized in relation to those from the Medical Course of the University of Coimbra[5]. At the Porto School, for example, three military faculty members stood out: Roberto Frias, Lopes Martins Júnior and Maximiano de Lemos (a major figure among those who dedicated themselves to the History of Portuguese Medicine)[23]. The same Diploma provided for the creation of similar Schools in the Capitals of Overseas Administrative Districts. In this context, the Medical-Surgical Schools of Funchal (1837-1910), Ponta Delgada (1837-1839) and Goa (active since 1842, officially regulated in 1847, being the first Higher Education Institution in the whole Indian subcontinent), emerged[24]. In the latter, it was common for military personnel on commission in that territory to be appointed as professors, as was the case of Herculano de Sá Correia, the author's great-great-uncle, a naval surgeon, trained at the Medical-Surgical School of Lisbon, while serving in Goa and Macau between 1849 and 1853[25].

CONCLUSION

With this article we have provided a brief overview on the contribution of military surgeons to the teaching of surgery both within the Military Institution and in the Civilian Environment. In the latter case, not only in the foundation and teaching in educational establishments, but also congregating in societies that promoted scientific progress in the various areas of Medicine, Surgery and Pharmacy, as was the case of the Society of Medical Sciences of Lisbon. In this regard, we have rectified or clarified some aspects that current historiography and narratives tend to perpetuate, hoping to contribute to future research.

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JORNAL DA SOCIEDADE DAS CIÊNCIAS MÉDICAS DE LISBOA

The Origins of the Journal of the Lisbon Medical Sciences Society

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ABSTRACT: The need of update was acutely felt by Portuguese surgeons and physicians in the early XIX century when contacting with their French and English military counterparts during the Napoleonic invasions of Portugal (1807-1810). This led to the creation of a medical forum overcoming the scarcity of scientific information in a country far away from the most advanced medical centers. Then, the *Sociedade das Ciências Médicas de Lisboa* (The Medical Sciences Society of Lisbon) was founded in 1822, beginning immediately with the organization of regular scientific meetings. The aim of this society also included the scientific assistance to the national health authorities and the spread of scientific information to the medical community throughout the country, reaching professionals at distant and isolated regions where no other source of updated should be attained. So, a medical journal was created with its first issue being published in January 1835. Inevitably, during such a long period many political, social and sanitary turmoil occurred but the journal survived, being one of the elder medical publications worldwide. Nowadays a new era began by becoming the official journal of the two medical schools in Lisbon and so strengthening the aim of this 189 years old medical journal.

KEY WORDS: Sociedade das Ciências Médicas de Lisboa, Jornal da Sociedade de Ciências Médicas de Lisboa, Origins of the Medical Journals, Origins of the Portuguese Medical Schools in the XIX Century

THE HISTORY

The Sociedade das Ciências Médicas de Lisboa (Lisbon Medical Sciences Society) (SCML) held its first (preparatory) session on June 28, 1822, at the Convent of S. Francisco da Cidade, where, since 1817, the Regimental Hospitals wards were located. Fourteen military surgeons and physicians were present.

The following day, during a new meeting, it was decided to increase the number of members to a total of 21, by also admitting pharmacists. These individuals constituted themselves as "institutors". They were 8 physicians, 10 surgeons and 3 pharmacists.(1)

This fulfilled the needs felt by healthcare professionals, acknowledging the lag of Portuguese Medicine and Surgery in comparison to its counterparts across Europe. Interaction with French and English military surgeons since the Seven Years' War, followed by the Napolionic Invasions and subsequent periods, highlighted this egregious situation.

The purposes of this Society were defined as follows:

> *"to establish ties with more qualified physicians and surgeons in Portugal or abroad".* (1)

They were also concerned about the need to submit new or already existing medicines to a scrupulous evaluation for new formulations or presentations. To meet this

aim, several criteria were defined. Public health concerns were also expressed, so the Society aimed to divulge, by means of publications, the various endemic or epidemic diseases that might occur and also provide recommendations on public health affairs.

Several other meetings took place before the solemn "Founding Session" which took place at the large hall of the Convent's library, previously adapted to military hospital, on December 1, 1822. This date was chosen due to the symbolism of the Restoration of Independence Day, December 1, 1640.

On January 11, a delegation was received by the king D. João VI at the Bemposta Palace. After the presentation of the Society and their purposes, the king said: "I greatly praise the foundation of a society that may provide great services to the Kingdom and I always will provide it with all possible protection."[2]

Despite such good auspices and the enthusiasm of the participants, as can be anticipated by the high number of sessions held (24 in a period of 6 months), its activity was interrupted in June 1823, due to the dissolution determined by the new absolutist regime, allegedly because it was "a focus of conspiracy and protest against the triumphant royal policy".[2] This led to a few of its members to seek exile.

However, the commitment to scientific progress was indomitable and overcame the obscurantism. Thirteen years later, in 1835, with the political constitution returning to normalcy, the SCML experienced a resurgence under the leadership of the same president, Francisco Soares Franco, a professor at the University of Coimbra. This demonstrated unequivocally the steadfast determination of its members.

In fact, on May 16, 1835, in a notice published in the Official Gazette, doctors, surgeons and pharmacists were summoned to a meeting at the Associação Mercantil Lisbonense to restore the SCML.[3]

THE BACKGROUND

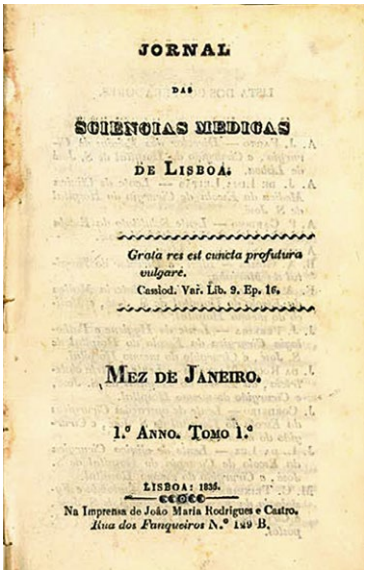
Even after death, the proclamation of Manoel Constâncio's (1726-1817) ideals, as published in the Official Gazette, continued to resonate through the corridors of the Hospital de S. José, etching itself into the memories of his disciples: it was necessary to promote the training of surgeons, providing them knowledge in the academic sphere and expertise that might only be acquired in the most developed European centers. He himself, motivated some of his disciples to go abroad (to England and Denmark), which was an innovation in the Portuguese context.[4] Constâncio fought for the foundation of a School dedicated to surgery. However, he did not see the results of his efforts, as he died in 1817 at the age of 91. However, the enduring relevance of his vision inspired the foundation of the Régia Escola de Cirurgia, (The Royal Surgery School) in 1825, which was followed by the Escola Médico-Cirúrgica de Lisboa (Lisbon Medical-Surgical School), in 1836. There is, therefore, an almost perfect overlap between the dates of the restoration of the SCML and the foundation of the surgical and medical teaching schools, reflecting a general awareness for the need of the development of health sciences in Portugal.

THE JOURNAL

This marked an era of remarkable dynamism, breaking large times of stagnation. While the enlightenment century arrived later for us, as tradition dictated, its impact was undeniable. Within this backdrop emerged the imperative to establish a 'Society of Medical Sciences,' a forum designed to foster comprehensive peer reflection on the future directions of national medical practice. This encompassed all facets, including pharmacy, while simultaneously ensuring the dissemination of the most recent advances in these fields. It was recognized as an indispensable pathway for the professionals to remain abreast on this ever-evolving landscape. Furthermore, it seemed necessary to create a publication to publicize and preserve the memory of the Society's activities.

Even before the restoration of the Society, the "Jornal das Sciencias Médicas de Lisboa" appeared in January 1835 (fig. 1), and continued into the next year, bearing the name it holds to this day: Jornal da Sociedade das Ciências Médicas de Lisboa (Journal of the Society of Medical Sciences of Lisbon – JSCML) (fig. 2). It should be noted that the motto "Grata res est profutura vulgare" was written on its front page since the first issue, which can be freely translated as: "Everything that benefits the people is a good thing".

Thus, in the Prospectus (preface) of the aforementioned first issue of the JSCML, its purpose was clearly established: "The rapid progress of medical sciences in the last few years, the influx and variety of writings that, due to the continuous and incessant number of works on the different branches of the art of healing enriching science every day, have made medical


JORNAL
DAS
SCIENCIAS MEDICAS
DE LISBOA.

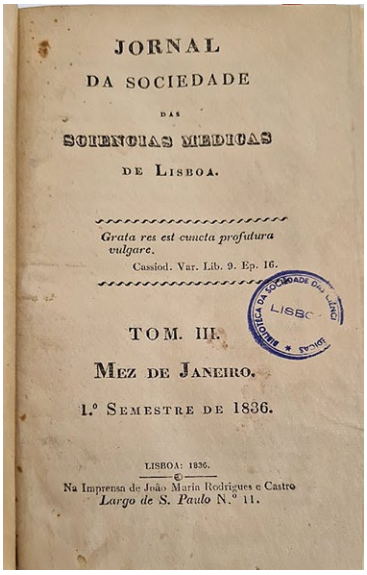
Grata res est cuncta profutura vulgare.
Cassiod. Var. Lib. 9. Ep. 16.

MEZ DE JANEIRO.

1.º ANNO. TOMO 1.º

LISBOA: 1835.
Na Imprensa de João Maria Rodrigues e Castro.
Rua dos Funqueiros N.º 149 B.

Fig 1. Cover page of Journal of the Medical Sciences of Lisbon – January, 1835 (FMUL Library)


JORNAL
DA SOCIEDADE
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DE LISBOA.

Grata res est cuncta profutura vulgare.
Cassiod. Var. Lib. 9. Ep. 16.

TOM. III.

MEZ DE JANEIRO.

1.º SEMESTRE DE 1836.

LISBOA: 1836.
Na Imprensa de João Maria Rodrigues e Castro
Largo de S. Paulo N.º 11.

Fig 2. Cover page of Journal of the Society of Medical Sciences of Lisbon – January, 1836. (FMUL Library)

journals, of such an high quality publications, absolutely necessary. The multiplicity of these works, and the acquaintance they receive everywhere, are one of the most evident proofs of their real merit, which, moreover, is naturally deduced from the ease with which such writings can readily convey observations, experiences and, in short, all the novelties that have occurred in science, without which, only later, or perhaps never, would they be known, given the difficulties of their authors in getting them published."[5]

The prestige of the SCML and its newspaper can be gauged by the exchange it maintained with its European counterparts, one such example was the controversy that took place in 1914 between Ricardo Jorge, then president of the SCML, and C. Mense, director of the Archiv für Schiffs und Tropen-Hygiene owing to the fact that Ricardo Jorge published an article in JSCML producing some comments deploring the beginning of the world conflict. This prompted a reply from C. Mense, accusing Ricardo Jorge of being "anti-Germanophile", which led to the end of the exchange between the publications.[6]

The times went by with the usual sociopolitical vicissitudes, to which the Society and its newspaper could not remain indifferent. The frequency of publication, initially monthly, underwent changes throughout the years.

In the report of the Secretary of SCML for the academic year 1973/1974, it was noted: "the great difficulties in obtaining scientific material for publication from the different sections".[7] The journal underwent a reformulation in 1983 adopting a more spaced and irregular periodicity. It became annual from 2000 to 2003 and then experienced a period of lethargy.

The contingencies that long-lived societies often go through often end up reinforced by these setbacks.

Thus, the Jornal da Sociedade das Ciências Médicas de Lisboa, one of the oldest medical publications in the world, still active, now re-emerges revitalized as the official journal of the Faculty of Medicine of the University of Lisbon and the Faculty of Medical Sciences of the Universidade Nova of Lisbon, endorsing to its members the gratifying undertaking of pursuing it.

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JORNAL DA SOCIEDADE DAS CIÊNCIAS MÉDICAS DE LISBOA

Children's Health and Well-Being: from the 19th to the 21th Century

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ABSTRACT: Child healthcare was scarce till the second half of the 19th century and only in 1989 were children's rights officially acknowledged in the Convention on the Children Rights. But health is just one dimension of well-being that includes all domains of quality of life, whether physical, emotional, or social.

Nowadays, health indicators related to children are a matter of pride not only for the progress made but also for achieving similar values to other countries in the European Union.

Undoubtedly, from the 19th century to the 21st century, since the creation of the Sociedade das Ciências Médicas, the evolution of health in Portugal, notably children's health with the establishment of the National Health Service and proper planning, has allowed for significant and recognized gains.

KEY WORDS: Child healthcare

The oldest book in Sociedade de Ciências Médicas' Library, published by Garcia de Orta in 1563 was entitled "***Colóquios dos simples e drogas he cousas medicinais da Índia*** (1) *e assi dalgũas frutas achadas nella onde se tratam algũas cousas tocantes a medicina, pratica, e outras cousas boas pera saber."* Beyond the remarkable text, there is a preface from his friend and famous poet Luís de Camões who also lived in Goa and was the author of the epic poem Os Lusíadas.

Despite having searched through the library's 2300 books published since the 16th century, only three books were printed of child health by the end of the 19th century. The first identified is ***Traité des Maladies des Enfants,*** by Michael Underwood (Edition 1803) (2).

Underwood's book has chapters dedicated to various subjects, including mouth ulcers, cutaneous eruptions, diarrhea or crying babies. Prescriptions are astonishing, as the example of an ointment for cutaneous eruptions:

Cantharides en poudre, une once;
Faites bouillir dans demi-livre d'eau de Fontaine,
Reduisez à quatre onces
Ajoutez de basilicum jaune, quatre onces
Faites cuire jusqu'à ce que toute l'eau soit evaporée

Nowadays, cantharides are used to treat warts or as an aphrodisiac beverage!

Examining the almost 600 volumes of the Society Scientific Journal (published on a regular basis from 1835 to 1974), there are some reports of 16 or 17-year-olds but they were not considered children and there are also anecdotal cases like a 4-year-old found with a fetus in her peritoneal cavity, the likelihood of it being a deceased twin. From 1920, there are many monographs by the northern obstetrician Costa Sacadura on pregnancy or labour, however they never mention the newborn.

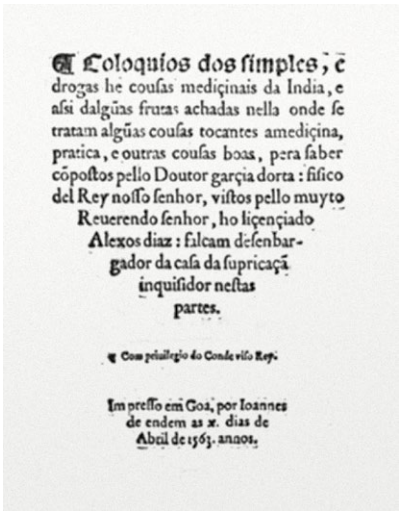
Given the high mortality rate below 5 years old, children did not have recognized a existence. Quoting Aristotle *"... children are irrational, unfinished and imperfect beings"*. Much more attention was paid to them by the medical community in the second half of the 19th century and only in 1989 were children's rights officially acknowledged in the Convention on the Children Rights (3).

The large-scale employment of children (from as early as 8 years old) during the industrial explosion of the late 18th century was common despite the knowledge that child labour was a form of child abuse and almost half of child "worked" in hazardous industries. Ambroise Tardieu, forensic medical doctor, studied all types of violence and abuse in children, including exposure to hazardous conditions on factories and coal mines and its results on their physical and mental health (4). And a recent research by Gowland found evidence that these children were fed a diet low in animal protein, severe growth delays and respiratory disease suggesting early life adversity and dangerous conditions in these children (5).

On the early 20th century, children were still seen as an *adult's thumbnail and parents'* property whose own interests prevailed. Care was limited to hygiene and nutrition and education, early work or medical support was a father's decision since disease was considered a moral regeneration process.

The *Hôpital des Enfants Malades* in Paris (1802) was the first centre in Europe dedicated to the exclusive medical care for children. It was followed by similar institutions in London, Berlin, Vienna, Boston and St. Petersburg (1869) although there are reports on the Hospital de Ninos Pedro de Elizalda (Buenos Ayres) since 1779 (6).

In 1853, Abraham Jacobi, concerned about the high infant mortality rate, founded a new medical specialty named Pediatrics based on the Greek words 'paidos' (child) and 'iatrous' (cure process) (7). Isaac Arthur Abt created the American Academy of Pediatrics and the Children's Hospital of Philadelphia, which placed a strong emphasis on research from its inception, two years later.


Colloquios dos simples, e
drogas he cousas mediçinais da India, e
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pratica, e outras cousas boas, pera saber
cõpostos pello Doutor garçia dorta: fisico
del Rey nosso senhor, vistos pello muyto
Reuerendo senhor, ho liçençiado
Alexos diaz: falcam desenbar-
gador da casa da supricaçã
inquisidor nestas
partes.

Com priuilegio do Conde viso Rey.

Im presso em Goa, por Ioannes
de endem as x. dias de
Abril de 1563. annos.


TRAITÉ
DES
MALADIES DES ENFANS,
PAR M. UNDERWOOD, D. M.
Membre du Collège Royal des Médecins de Londres;
Auquel on a joint les Observations-pratiques de M. Armstrong, D. M. premier Médecin de l'Hôpital des pauvres enfans de Londres, & celles de plusieurs autres Médecins.
TRADUIT DE L'ANGLOIS.
ARS LONGA.
Hippocr.
A PARIS,
Chez THÉOPHILE BAROIS le jeune, Libraire, quai des Augustins, N°. 18.
M. DCC. LXXXVI.
Avec Approbation, & Privilège du Roi.

Fig 1. *"Colóquios dos simples e drogas he cousas medicinais da Índia"*, front page by Garcia de Orta.

Fig 2. "*Traité des Maladies des Enfants, by Michael Underwood"* front page by Underwood. 1st Edition hardcover and content.

In Portugal, a milestone in child care was reached with the establishment of Hospital de Dona Estefânia (1877), built at the request of Queen D. Estefânia, who used to visit the patients in hospitals with her husband D. Pedro and was impressed to see children alongside to adults and elderly. Children's diseases were infectious such as mumps, whooping cough, diphtheria, and scarlet fever or related to malnutrition (8).

The first pediatrician was Sara Benoliel (1867-1955), the Portuguese Pediatric Journal was established in 1938 by Carlos Salazar de Sousa. And HDE was the headquarters of the Portuguese Society of Pediatrics at its founding in 1948 by the De Sousa with Manuel Cordeiro Ferreira, Almeida Garrett (Porto) and Lúcio de Almeida (Coimbra).

However, actions had already been taken and portuguese legislation on public health emerged particularly concerning the prohibition of litter in public roads, manure piles or water puddles, as well as public disinfection and notification of diseases such as cholera, typhus, yellow fever, plague, smallpox, and scarlet fever.

A sanitary authority figure was created to assist doctors in providing instruction and prevention. Additionally, a sanitary park for disinfection and pest control of equipment, vehicles, clothing, tents, greenhouses, mobile hospitals, and laboratories was settled.

Yet, child health care improvement only began in the 1980's. In this third decade of the 20th century, health indicators related to children (defined by the age of 0 to 18 years by the World Health Organization) in Portugal are a matter of pride not only for the progress made but also for achieving similar values to other countries in the European Union.

Maternal and child health in Portugal is mentioned in the World Health Organization's World Health Report in 2008: "... infant mortality rate consistently and rapidly dropped from 77.5 in 1960 to 3.6 per thousand, as a result of the improvement in the socio-economic conditions of the Portuguese population and global health reforms with specific interventions in those areas (9). The medical journal Lancet also noted in 2014 that Portugal was one of the 10 safest places in the world to be born (10) and a low mortality rate under 5 years of age places Portugal among the top 10 in the world, together with Japan, Norway, Sweden, and Finland.

This successful story happened through political will by the Minister of Health Leonor Beleza who recognized the importance of this area; through the planning and implementation of strategies by the first National Commission for Maternal and Child Health (CNSMI) which are an example of best practices. Appointed ministerially in 1986, the CNSMI included the obstetricians Albino Aroso and Dória Nóbrega, and the pediatricians Torrado da Silva and Octávio Cunha who found a disastrous scenario, maternity wards without basic conditions of human resources and equipment while others had an excess of professionals and scarce utilization of medical machinery (11).

There was no coordination between levels of care and no specific training for professionals. A year later, the CNSMI program was approved by the health authorities to be implemented over 9 years, in phases with goals set for every 3 years. This included the organization and concentration of care, the requalification of maternity wards and neonatology services defined as Perinatal Support and Differentiated Perinatal Hospitals, regionalization and referral networks, coordination with Primary Care, and exemption of co-payments for pregnant women and children under 12 years old. Special post graduation and training programs were also organized for neonatologists and other professionals. Functional Coordinating Units, the famous UCFs, were established with the purpose of regular meetings between medical, nursing, and social work professionals from primary health care centers and hospitals to solve common problems.

And, in the 21th century, a a portuguese girl born in 2022 has a potential life expectancy of 83.52 years, while a boy has a life expectancy of 78.05 years (12). Mortality has significantly decreased globally from 0 to 19 years old, across all age groups. Almost all newborns benefit from neonatal screening and 99% of children have completed the National Vaccination Program by the age of 6. The percentage of children in the 1st cycle of education who are overweight or obese has also decreased. Nitety one per cent 91% of children and adolescents have a General Practitioner assigned, but there are significant asymmetries among the 7 major regions in Portugal, particularly in Madeira and The Azores Islands (13).

But health is just one dimension of well-being that includes all domains of quality of life, whether physical, emotional, or social. UNICEF considers six dimensions that measure well-being: material (poverty, family unemployment, low level of parents' education), health and safety (infant mortality, low birth weight, vaccination rate, and accident mortality), education (academic success in reading, math, and science), family (family typology and intrafamily relationships), health

risk behaviors (breakfast habits, fruit intake, daily physical activity, overweight), and/or violence (abuse, neglect, bullying) and subjective factors (perception of health, enjoyment of school, feeling of happiness) (14).

Portugal is one of the European countries with the most gains in education, a fundamental factor in correcting inequalities and promoting the Country's development and 90% of the population has at least 4 years of schooling. The early school dropout rate has significantly decreased, but it is still higher in boys, as is also the case in other European countries.

Regarding social aspects, the risk of poverty in childhood and adolescence is still significant, although it decreased after social support. Portugal is the 4th country in the EU23 European Union with the highest number of families with 3 or more children and risk of poverty in single-parent households, even higher if female-led. As for the protection of children and young people in danger, Portugal has an exemplary organization that has been able to prevent and intervene by working with the families, keeping the children with their parents or another family member.

Portugal's major regions show significant asymmetries: the Lisbon Metropolitan Area and the Algarve are younger, while the Azores, Madeira, and the North are older and have experienced greater losses of children and teenagers. The balance between immigrants and emigrants in this age group is positive and more pronounced in the Lisbon Metropolitan Area and the Algarve.

More than half of births occur outside of marriage, and nearly one-fifth of parents of all newborns do not live together. Only three countries in Europe have higher percentages of unmarried parents, with France in first place (59.9%). The maternal age at the birth of the first child has increased, with maternity after the age of 40 doubling in almost all regions and tripling in the Lisbon Metropolitan Area.

Mothers have a higher level of education and literacy. Over the past 20 years, there has been an 11% increase in those who have completed secondary education, and the number who have completed higher education more than doubled.

The most common profile of the Portuguese family is a couple with one child, while European families more frequently have two or more children. Divorces have increased, putting Portugal in the top position among EU countries in this indicator in 2017, followed by Luxembourg and Spain. Since the beginning of the millennium, single-parent households have continued to increase and are predominantly matriarchal, with no significant differences between regions.

Undoubtedly, from the 19th century to the 21st century, since the creation of the Sociedade de Ciências Médicas, the evolution of health in Portugal, notably children's health with the establishment of the National Health Service and proper planning, has allowed for significant and recognized gains.

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RESEARCH ARTICLE

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Feasibility of using risk reminders to prevent falls, dehydration and pulmonary aspiration in nursing homes

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ABSTRACT: Background: Previous research has indicated an increased risk of dehydration, falls, and pulmonary aspiration among older adults in nursing homes, negatively impacting independence and quality of life. To provide high-quality care and prevent risks, it is crucial to be aware of residents' difficulties, implement risk minimization strategies, and effectively communicate this information to all nursing home staff. This study aimed to evaluate the feasibility of using a set of risk reminders designed to caution against fall, dehydration, and pulmonary aspiration risks. **Methods:** All residents from CNS - Campus Neurológico were invited to participate if they met the eligibility criteria. At baseline, residents underwent a screening risk assessment, and corresponding risk reminders were assigned. The study included a daily record of falls, dehydration, and pulmonary aspiration events, as well as monthly interview assessments. Event data were compared with historical data extracted retrospectively from medical and nursing charts. **Results:** A total of 23 CNS residents participated in the study. Residents median satisfaction score on a 7-point Likert scale was 3.4 ± 0.2 (quite satisfied). Healthcare professionals assessed satisfaction and usability mean scores were 2.4 ± 0.2 (very satisfied) and 2.2 ± 0.1, respectively. The mean number of times per user that bracelets were removed was 1.78. The main reasons for removal included: lack of adjustability, forgetting the purpose of the bracelets, and a lack of habit. **Conclusion:** The results showed good adherence and acceptance of risk reminders by both residents and health professionals. Further studies are needed to investigate their efficacy in decreasing events in nursing homes.

KEY WORDS: Nursing home, falls, dysphasia, pulmonary aspiration, dehydration

INTRODUCTION

Given the increased life expectancy, the number of older adults living in nursing homes is expected to considerably rise over the next few decades [2,3]. Nursing homes provide 24-hour nursing care to residents with varying degrees of functionality and a wide array of health-related problems [1]. The necessity for

strategies to minimize safety risks and to maintain the quality of life and autonomy of residents is now imperative [2,3].

Falls, choking, pulmonary aspiration, and dehydration pose significant challenges in nursing homes, contributing significantly to the deterioration of independence and residents' quality of life [4–9].

The incidence of falls and fall-related injuries among individuals in institutions has been reported in several studies, emerging as a major external cause of death in nursing homes [2,10,11]. Compared with elderly persons living in the community, the mean fall incidence is three times higher, with an average of falls per bed per year in nursing homes being 1.5. Moreover, the incidence of falls in demented patients is two to three times higher, with weakness and gait problems being the most common causes [10,11].

Aspiration pneumonia is another major problem. It is particularly challenging to diagnose since the moment of aspiration is usually not observed. According to an Australian study on external-cause deaths of nursing home residents [2], choking was the most common external cause of death in residents younger than 65 years. Important risk factors for aspiration pneumonia include dysphagia, old age, male gender, lung diseases, diabetes mellitus, poor oral health, severe dementia, Parkinson's disease, malnutrition, and the use of antipsychotic drugs, proton pump inhibitors, and angiotensin-converting enzyme inhibitors [12].

Dehydration, due to poor fluid intake or pathological loss of body fluids, was present in 0.8% to 1.4% of nursing home residents, with a 6-month incidence of dehydration of 1 in 3. It is associated with frailty, poor cognition, falls, delirium, disability, and mortality [13]. Additionally, dehydration is a major cause of decreased attention and fluctuating mental status, which are hallmarks of delirium [13].

These conditions are preventable. However, to provide high-quality care, nursing home staff needs to function as a coordinated team, possess an effective communication system, and better understand the needs of residents [1]. The aim of this study was to evaluate the feasibility of a set of risk reminders, as part of a risk prevention strategy, to communicate falls, dehydration, and pulmonary aspiration risks and to help formulate tailored interventions to manage these events in nursing homes.

METHODS/DESIGN

Study design

A national, single-centre, feasibility study with a duration per participant between 3 and 5 months was conducted.

Study participants

Study participants were recruited from CNS - Campus Neurológico, a tertiary specialized neurological disorders center in Portugal, which includes a nursing home. All inpatients at CNS were invited to participate if they met the eligibility criteria. Patients were included if they resided at the CNS nursing home for long-term care, exhibited a risk of falling, dysphagia, and/or dehydration as determined by a brief screening assessment, and agreed to participate and comply with study requirements. Exclusion criteria involved the presence of significant active psychiatric problems (e.g., hallucinations, confusion, psychosis), which, based on the clinical judgment of the CNS multidisciplinary team, could be exacerbated by the use of risk reminders.

To prevent potential devaluation of risk reminders by nursing home staff, only residents with moderate to severe risk were considered candidates for the use of these reminders. This selection was based on the results of the screening assessment and on investigators best judgment. Those with significant active psychiatric problems (e.g., hallucinations, confusion, psychosis) that could potentially worsen with the use of risk reminders were excluded. Ethic committee of Centro Académico de Lisboa Norte (CAML) approved the study (Ref. 176/15). All participants gave their informed consent before any study-related proceedings or, if dementia was present, the caregiver.

Study materials

Risk reminders were created by the CNS risk reminders study group and were used by study participants, once included in the study, in their daily routines at the CNS. They include the following standardized materials (Figs. 1 and 2):

- Small, lightweight rubber-coloured bracelets, for residents' use (on the wrist, visible), with phrases related to the different risks: "prevent to not fall", "contain to protect", "drink to hydrate", and "avoid choking".
- Small and coloured signposts next to the residents' headboard in their rooms

Fig 1. Coloured bracelets with slogans related with the different risks

Fig 2. Coloured signposts next to residents' headboard

Study Procedures

Demographic information, clinical manifestations, and disease management data were gathered using a structured questionnaire. Additionally, a brief clinical assessment of the risk of falls, pulmonary aspiration, and dehydration was conducted.

At the end of each nursing shift, all events—falls, near falls, dehydration, and pulmonary aspiration—were documented using forms specifically created for this purpose by the CNS Risk Reminders Study Group.

At the end of each month, residents underwent an interview conducted by an investigator, and healthcare professionals completed a self-administered questionnaire. Both groups were queried about satisfaction and any encountered problems related to the use of risk reminders. Healthcare professionals were asked to evaluate usability in a 7-points Likert-scale. If dementia was present, only the occurrence of adverse events and the reason for not conducting the interview were recorded.

Furthermore, historical data regarding falls, dehydration, and pulmonary aspiration events for all CNS residents were collected retrospectively from medical and nursing charts within the study period and for the corresponding period the year before.

Statistical Analysis

The statistical analysis was conducted using SPSS® version 21.0 by SPSS Inc., Chicago, IL. Data were described using descriptive statistics. Our primary outcome focused on measuring residents ' adherence to risk reminders by recording the number of times and reasons they removed, refused, or withdrew from the study during the study period.

The secondary outcomes included:

1) Residents' satisfaction with the risk reminders, assessed on a 7-point Likert scale and through open-ended questions at the end of the study.

2) Healthcare professionals' satisfaction with the risk reminders, measured on a 7-point Likert scale, along with open-ended questions exploring the overall benefits of using the displays and their perception of the impact on decreasing risk, at the end of the study.

As an exploratory outcome, we characterized the events that occurred in the nursing home for all CNS inpatients based on electronic clinical records during the 5-month study.

RESULTS

Between October 2016 and February 2017, there were 104 inpatient subjects at CNS, with a median hospitalization duration of 29 days [4–151 days]. Of these, a total of 23 CNS residents met the eligibility criteria and were included in the study. The participants' mean age was 80.1 ± 8.6, and 56.5% (n=13) were female. The most common diagnoses were Alzheimer's disease (30.4%, n=7), Parkinson's disease (17.4%, n=4), and stroke (13.0%, n=3). Cognitive impairment was present in 52.2% (n=12) of the participants. Following the screening assessment and multidisciplinary team discussion, all residents were identified as having a risk of falls and dehydration, 65.2% (n=15) of pulmonary aspiration, and 39.1% (n=9) as requiring restraint (Table 1).

Residents' adherence

No residents refused the use of risk reminders during the study period. According to residents' interviews, the mean number of times per user that bracelets were removed was 0.4, while health professionals'

TABLE 1. Demographic and clinical characteristics of residents participating in the study

Residents' demographic data (n=23)	
Age (Mean, SD)	80.1 ±8.6
Gender (% Female)	56.5% (13)
Residents' clinical data (n=23)	
Diagnosis (%, n)	
Alzheimer's disease	30.4% (7)
Parkinson's disease	17.4% (4)
Stroke	13.0% (3)
Frontotemporal dementia	8.7% (2)
Lewy body dementia	8.7% (2)
Bipolar disorder	8.7% (2)
Multiple system atrophy	4.3% (1)
Progressive Supranuclear Palsy	4.3% (1)
Corticobasal degeneration	4.3% (1)
Cognition	
MMSE (n=18, Mean, SD)	19.4 ±7.8
Falls	
History of falling (%, n Yes)	13% (3)
Morse Scale (%, n High risk)	47.8% (11)
Time Up and Go	
Mean time (n=3, Mean, SD)	17.7 ±10.
Not applicable (bedbound, walking aids)	487% (20)
Pulmonary aspiration	
Presence of history of Pulmonary aspiration (%, n)	30.4% (5)
Presence of severe dysphasia (%, n)	8.7% (2)
Presence of impulse behavior disorder (%, n)	17.4% (4)
Swallowing Disturbance Questionnaire (n=21, Median, range)	4 [0,20]
Dehydration	
Presence of history of dehydration (%, n)	0%, 0
GULP assessment	
Low risk (%, n)	17.4% (4)
Medium risk (%, n)	78.3% (18)
High risk (%, n)	4.3% (1)

TABLE 2. Feasibility and safety data

Adherence	
Bracelets removal (mean nº of times the bracelet was removed/user)	
Based on residents' interview	0.4
Based on healthcare professional questionnaire	1.8
Dropouts	
Delirium (not related with the intervention, n)	1
Discharge from CNS (n)	3
Died (not related with the intervention, n)	1
Satisfaction	
Residents (Mean, SD)	3.4 ± 0.2
Healthcare professionals (Mean, SD)	2.4 ± 0.2
Usability	
Healthcare professionals (Mean, SD of 7-points Likert scale)	2.2 ±0.1
Problems reported by residents	
Fall off (n)	1
Hinder the movements (n)	1
Discomfort during the night (n)	1
Safety	
Reported events of interest	
Falls (n ǀ n/participants)	20 ǀ 0.9
Choking (n ǀ n/participants)	14 ǀ 0.6
Dehydration (n ǀ n/participants)	0 ǀ 0.0
Reported adverse events	
Hand edema (n)	1
Skin rash (n)	1

records indicated 1.8 removals. Since risk reminders included signposts next to residents' bed headboard, participants were allowed to remove bracelets overnight, and these removals were not considered in the adherence analysis.

The most common reasons for removing the bracelets during the day were their lack of adjustability, forgetting the purpose of the bracelets, and a lack of habit.

Five residents dropped out during the study: one due to a psychotic break, one passed away, and three were discharged from CNS (Table 2).

Residents and health professionals' satisfaction and usability

Residents' mean satisfaction with the risk reminders was 3.4 ± 0.2 (quite satisfied).

Residents' complaints about the use of bracelets included one complaint about bracelets falling off the arm frequently, one stating that it hinders movements, and one expressing discomfort during the night. Regarding the open questions at the end of the study ("what do you like most?" and "what you like least?"), all

but one respondent stated that they had nothing to say. One participant mentioned that the colour was what they liked most, and what they liked least was its lack of adjustability, causing it to fall off.

Health professionals' mean satisfaction with the risk reminders was 2.4 ± 0.2 (very satisfied) and the mean usability score of 2.2 ± 0.1 (very useful). The most valued aspects of risk reminders in their opinion were providing a better and easy way to alert for residents' risks, assisting in improving personalized integrated care. They also valued the colours and messages. The least appreciated aspects were the ease of hiding under clothing, lack of adjustability, and hindrance during bathing, dressing, and transitions. The most frequent suggestions from both groups were to have a bracelet that symbolizes all risks, to change the type of material, make it adjustable, and ensure visibility regardless of the residents' clothing (Tables 2 and 3).

TABLE 3. Healthcare professionals' comments on risk reminders

What do you like least?	
Visibility issues (due to clothing, n)	16
Lack of adjustability (n)	10
Challenges with bathing/dressing (n)	9
Challenges with transitions (n)	3
The material causes discomfort for patients (n)	2
Bracelets can be easily removed by patients (n)	2
What do you like most?	
Better and easy way to alert for the patients' risks (n)	56
Optimizes personalized integrated care (n)	10
The colors and phases (n)	8
Improves communication (n)	5
Potentiates multidisciplinary intervention (n)	4
Suggestions for improvement	
A bracelet that symbolizes all risks (n)	8
Change the type of material (n)	3
Being adjustable (n)	3
Ensure visibility regardless of patient's clothing (n)	3

Adverse events

Hands oedema (n=1), unrelated to the use of bracelets according to the clinical team, and a mild skin rash in the wrist area (n=1) were the only adverse events reported during the study (Table 2).

Characterization of events based on electronic clinical records

During the 5-months of the study period, the frequency of events/occupied beds (n=104) was 0.41, with 78.5% (n=84) of the residents without having any event, 15.4% (n=16) with one or more falls and 9.6% (n=10) having one pulmonary aspiration event.

In this 5 months, 25 falls events occurred, of which 6 were near falls. The most common periods were until 11:00 and from 2:00pm to 8:00pm. Bathroom (28%, n=7), followed by living room (20%, n=5) and dining room (12%, n=3) were the places in which the events more frequently occur. Thirty-two percent (n=8) had no consequences and 16% (n=4) caused soft-tissue injuries. In relation to pulmonary aspiration events (n=18), 61.1% (n=11) occur during the meals, 66.7% (n=12) with fluids. None of them have consequences (Table 4).

There were no dehydration events. Five residents removed the restrains, two of them more than one time.

DISCUSSION

A total of 23 residents and 131 answers from health professionals were included in this 5-months study. The mean age for study participants was 80 years old. All residents had some neurological disorder, the most common diagnoses were Alzheimer's disease (30.4%, n=7), Parkinson's disease (17.4%, n=4) and stroke (13%, n=3). Twelve (52.2%) participants had cognitive impairment, limiting the ability to collaborate in the monthly interviews.

Feasibility of risk reminders

Regarding adherence, the frequency of residents that remove the bracelets, during the day, was low (mean number of times per user that bracelets were removed was 1.78).

Residents and health professional were quite or very satisfactied with the risk reminders, respectively. Both agree bracelets need to be adjustable and to create a new one that symbolizes all risks. Visibility issues

TABLE 4. Characterization of events in the nursing home

Demographic data (n=104)			
Age (Average, SD)			75.8 ± 10.7
Gender (% Female)			51% (53)
Number of hospitalization days (Median, Min, Max)			29 [4,151]
Clinical data			
Diagnosis (%, n)			
Parkinson's disease			22.1% (23)
Stroke			13.5% (14)
Dementia syndromes			9.6% (10)
Alzheimer's disease			8.7% (9)
Lewy body dementia			7.7% (8)
Atypical Parkinsonism			4.8% (5)
Multiple system atrophy			3.8% (4)
Progressive Supranuclear Palsy			3.8% (4)
Bipolar disorder			3.8% (4)
Frontotemporal dementia			2.9% (3)
Traumatic brain injury			2.9% (3)
Vascular Parkinsonism			2.9% (3)
Others (n ≤ 2)			13.5% (14)
Patients with at least one event of interest			78.5% (84)
Events of interest			
Falls			
Total number of falls (n)		25	
Total number of near falls (n)		6	
Patients with at least one fall (%, n)		15.4% (16)	
Characterization of falls and near falls (%, n)	*Daytime period*	Until 11:00 am	36% (9)
		Until 2:00 pm	4% (1)
		2:00 - 08:00 pm	20% (5)
		After 08:00 pm	8% (2)
		Unknown	32% (8)
	Local	Bathroom	28% (7)
		Bedroom	4% (1)
		Dining Room	12% (3)
		Gymnasium	4% (1)
		Living room	20% (5)
		Unknown	32% (8)
	Consequences	Bruise	4% (1)
		Soft-tissue injuries	16% (4)
		Fracture	4% (1)
		No consequences	32% (8)
		Pain	4% (1)
		Unknown	40% (10)
	Register by	Nurse	80% (20)
		Physician	12% (3)
		Nurse/Physician	8% (2)

TABLE 4. *(continue)*

Choking events			
Total number of choking events (n)		18	
Patients with at least one choking event (%, n)		9.6% (10)	
Characterization of choking events (%, n)	*Daytime period*	Meals	61.1% (11)
		Taking medication	5.6% (1)
		Oral hygiene	5.6% (1)
		Unknown	27.8% (5)
	Cause	Fluids	66.7% (12)
		Solids	5.6% (1)
		Unknown	27.8% (5)
	Consequences	No consequences	100% (18)
	Register by	Assistive personnel	11.1% (2)
		Nurse	83.3% (15)
		Physician	5.6% (1)
Dehydration events			
Total number of dehydration events (n)		0	

were also frequently referred by health professionals. According to participants general opinion, this can be overcome by instructing nursing home staff to put the bracelets over the clothes or rolling up the sleeves so that the bracelets are always visible.

Despite these issues, health professional classified the risk reminders as very useful. They were considering a helpful and easy to use strategy to be alert for the residents' risks, to improve communication among health professionals of the multidisciplinary team and to optimize personalized integrated care.

Characterization of events

Our results showed that falls and choking events occur in a nursing home. Although we didn't register any dehydration events, we are aware that they are frequent in nursing homes. Our aim in conducting this characterization was to explore patterns related to location, time of day, or other characteristics associated with the events of interest.

Fall events

Data from electronic clinical records showed bathing time and the afternoon (between snack and dinner) as the most problematic periods, consistent with the locations where most of the falls occur (bathroom and living room). Mackenzie & Byles review [11], reported the bathroom and early morning as associated with a high frequency of falls due to the demands of the task, especially the high number of transfers needed. We hypothesize that the high frequency of falls during the afternoon is related to residents spending most of this time engaging in activities in the living room and our sample being mainly composed of residents with neurological diseases associated with gait problems. Most falls in our study did not have consequences, with only one recorded instance of a fall-related fracture. These results are supported by a previous review on falls and near-falls in nursing homes [10], which reported that individuals with substantial gait disorders have a prevalence of falls 2.4 to 4.8 times higher than those without gait problems. Additionally, the review found that only 4% of falls result in fractures.

Pulmonary aspiration events

The most common events of pulmonary aspiration occurred during meals, involving fluids and typically without consequences. These findings align with evidence demonstrating significant changes in the swallowing mechanism as people age. Elderly neurological patients, experiencing cognitive and perceptual changes alongside impaired functional status – characteristics prevalent in our population – are more likely to be associated with swallowing and eating impairments, leading to pulmonary aspiration events [15–17].

Dehydration events

In both electronic clinical records and diary records, no dehydration events were documented. Dehydration is typically associated with frailty, poor cogni-

tion, falls, delirium, and disability; thus, we expected to find some mild forms in our study [13]. Despite the teaching sessions provided to health professionals on how to detect mild forms of dehydration, these events are not as easily noticeable as falls. It is possible that some mild forms of dehydration might have gone unnoticed. There were no recorded hospital transfers for this reason

CONCLUSION

The use of risk reminders, given its simplicity, low complexity, and minimal physical requirements, appears to be an interesting tool for managing falls, pulmonary aspiration, and dehydration events in nursing homes. Our results demonstrated good adherence and acceptance of risk reminders by both residents and health professionals. It was viewed as a simple and effective method to stay alert to the risks faced by residents in nursing homes, serving as a strategy to optimize personalized integrated care.

Further studies are needed to investigate the efficacy of risk reminders in reducing the frequency of events in nursing homes.

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SYSTEMATIC REVIEW

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Clinical dashboards for Parkinson's Disease monitoring: a systematic review

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ABSTRACT: **Background:** Dashboards have been used in clinical settings to monitor Parkinson's disease (PD), serving as a means to visually represent collected data. However, there's a need to deepen understanding regarding the relationship between the types of data collected and the appropriate visualisation formats in clinical dashboards. Furthermore, the existing dashboards lack tailoring to the specific needs of both patients and healthcare professionals, and their clinical utility remains largely unexplored. **Methods:** We conducted a systematic review of the literature according to PRISMA guidelines based on the research protocol published at PROSPERO [CRD42021256047]. PubMed/MEDLINE, ACM and IEEE databases were searched in March 2024 for studies focused on developing and designing clinical dashboards for PD monitoring. **Results:** A total of 47 articles were included in the review. Sensors directly attached to the participant's body or embedded in various devices serve as the primary data collection tools. Among the included studies, most (39 out of 47) centred on monitoring motor symptoms such as tremors, bradykinesia, and dyskinesia, while only a small portion of the studies (8 out of 47) focused on other health-related outcomes. Notably, only a small fraction of studies (14 out of 47) involved end-users at some stage of system development, with only eight studies (8 out of 47) employing co-design or participatory design methodologies to develop dashboards with end-users collaboratively. **Conclusions:** This review underscores the prevalent use of sensors for gathering data on monitoring motor symptoms of Parkinson's Disease. Furthermore, our study also highlights a significant gap in end-user involvement in dashboard design, which impedes the advancement of knowledge regarding the optimal visual representation of clinical data.

KEY WORDS: Parkinson's Disease, Clinical dashboards, Data visualization, Disease monitoring

INTRODUCTION

Dashboards are visual means of representing and aggregating information (1). They enable the consolidation of data extracted from various sources (e.g., electronic devices) and facilitate user data navigation. There are various ways to display specific data, including tabular, textual, or graphical representations (1). Despite the existence of best practices for optimal information visualisation, it may be necessary to adapt the data presentation format depending on the user's needs (2).

Technology rapid advancements have introduced a multitude of devices into our lives, ranging from smartwatches to smartphones, each contributing to the generation of immense volumes of data (3). Dashboards serve as invaluable tools in organising this wealth of information. By aggregating and visually presenting data, dashboards facilitate comprehension and decision-making processes (4). Furthermore, they enable real-time monitoring and analysis, empowering users to respond promptly to changing circumstances.

In clinical practice, where a vast amount of information needs to be collected, whether through test batteries, questionnaires, or digital devices, dashboards can play a crucial role in facilitating consolidated access to this information (5). In healthcare, collecting and managing diverse datasets is paramount for effectively diagnosing, treating, and monitoring patients. Dashboards offer a centralised platform where healthcare professionals can efficiently access and analyse patient data, thereby streamlining decision-making processes and enhancing the quality of care. By aggregating data from various sources, including electronic health records, medical devices, and patient-reported outcomes, dashboards provide a comprehensive overview of patient health status and treatment progress (6).

Data collected from digital devices, complemented by appropriate visual representations such as dashboards, can prove highly beneficial for chronic diseases requiring continuous patient monitoring and management (3,7). This is particularly pertinent in the case of Parkinson's disease (PD), where not only is ongoing care necessary, but symptoms also fluctuate considerably over time and even throughout the day. Consequently, having access to consolidated information can significantly aid clinical practice.

Parkinson's Disease presents a unique set of challenges due to its progressive nature and the variability of symptoms experienced by patients. By leveraging data collected from wearable devices, smartphone applications, and other digital health tools, clinicians can gain valuable insights into the patient's condition beyond the confines of traditional clinical encounters (3,8). These insights enable personalised care planning, medication regimen optimisation, and early disease progression or complications detection. Moreover, the visualisation of longitudinal data trends through dashboards facilitates comprehensive assessment and promotes shared decision-making between patients and healthcare providers (4). Thus, the integration of digital health data with intuitive visualisations holds promise for improving the management and outcomes of PD and other chronic conditions requiring continuous monitoring and personalised care.

Several examples of utilising dashboards to enhance healthcare delivery and decision-making processes already exist (9,10). However, despite their promise, dashboards in clinical practice have yet to become a widespread reality. One of the reasons for this, is the lack of adaptation to the needs of healthcare professionals (11) and to evaluate their utility in clinical practice (12).

To the best of our knowledge, our work takes the initial step towards addressing the identified limitations by analysing the available literature on developing and designing clinical dashboards to monitor PD patients. For this purpose, we conducted a systematic review of the literature on clinical dashboards for PD monitoring. Through our efforts, we aim to contribute to the advancement of clinical dashboard design and progressively promote their integration into routine PD care, ultimately improving patient outcomes and enhancing the efficiency of healthcare delivery.

MATERIAL AND METHODS

This systematic review of the literature was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA 2020) (13) (S1 Table. PRISMA 2020 checklist), and it was based on a previous research protocol published at PROSPERO [CRD42021256047] (S1 File. PROSPERO Protocol)

Types of studies

To be included, studies had to present original data on developing clinical data visualisation dashboards intended for monitoring patients with PD. Articles considered for inclusion had to be published in English in peer-reviewed platforms such as journals and conferences. The search was not restricted by year of publication to avoid excluding potentially relevant articles.

Articles focused solely on technologies that do not aim to provide longitudinal evaluation of PD symptoms or those primarily concerned with PD diagnosis or screening were excluded. Additionally, reviews, study protocols, and grey literature, including case studies, books, book chapters, reports, thesis, editorials, and letters to the editor, were also excluded.

Electronic databases and search strategy

Electronic database searches on PubMed/MEDLINE, IEEE and ACM databases were conducted on the 26th of March 2024 using the following search string:

("Parkinson") **AND** *("monitoring"* **OR** *"assessment")* **AND** *("Report*"* **OR** *"dashboard"* **OR** *"data")* **AND** *("sensor*"* **OR** *"technolog*"* **OR** *"system*"* **OR** *"device*")*

For more information on database searches and search strings, see S2. Table Electronic databases and search strategies.

DATA EXTRACTION

The search results from the electronic databases were imported into Rayyan – Intelligent Systematic Review (14). Duplicates were automatically identified using Rayyan's built-in tool and manually excluded. Using the Rayyan platform, the remaining entries were independently screened by at least two reviewers (FFB, DB, MM) for title and abstract eligibility. Full-text evaluation and data extraction were performed using a spreadsheet. Any disagreements were resolved through reviewers' discussion or solved by a third party (TG or JJ).

Before the data collection process, we established consensus on concepts to ensure harmonisation among all team members during the data extraction process. According to our glossary:

- Technology to monitor health refers to objective measurement instruments to support clinical decision-making, including wearable sensors, sensors, electronic patient-reported outcomes (ePROs), robots, video cameras, and tablets/smartphones.
- Longitudinal monitoring refers to collecting evidence and evaluating a patient's condition over time, either through observation or objective quantification.

For data extraction, the following categories were included:

- Bibliographic information: title and study reference
- Study design: aim and context of the study, health-related outcomes, and technology employed
- Visual representation of clinical data: end-user involvement in dashboard design, methods, level of data visualisation, and dashboard/visual data representation descriptions

In the end-user involvement in dashboard design category, four sub-categories were considered: a) Software development, when papers solely focus on the development of new technology for PD monitoring; b) User validation, when participants (e.g., PD patients, caregivers, health professionals) were recruited and asked to test/use the system; and c) End-user involvement during design, when papers describe the use of co-design or participatory design techniques to inform how clinical data should be visually presented, and d) Longitudinal feasibility study, when end-users use the system for a certain period. For the level of data visualisation category, three sub-categories were considered: a) Basic, when the studies only mention the format in which feedback is given to end-users (e.g., report, a web application); b) Conceptual, when authors report the type of information they would like to visually represent in a dashboard (e.g., number of Freezing of Gait episodes) or use some graphic/visual representation of the data (e.g., a bar chart is used to represent how data can be display) but there is no dashboard; and c) Visual representation, when an interface is presented displaying clinical data after been submitted to some type of statistical analyses.

RESULTS

From the electronic databases search, 1182 records were initially identified (see Fig 1). Twelve records were excluded: ten duplicates and two ineligible records (e.g., retracted paper). After screening for title and abstract eligibility, 1025 records were excluded, leaving 145 records for full-text analysis. Upon full-text analysis, 98 articles were excluded, with the most common reasons being the absence of data visualisation (n = 74), data visualisation presented only during the data extraction phase (i.e., no data visualization related to PD monitoring) (n = 7), study focus was on PD assessment/screening, or the system developed was unrelated to monitoring of PD symptoms (n = 8). Finally, 47 articles met the inclusion criteria, and detailed information on these studies can be found in Table 1. Studies details (n = 47).

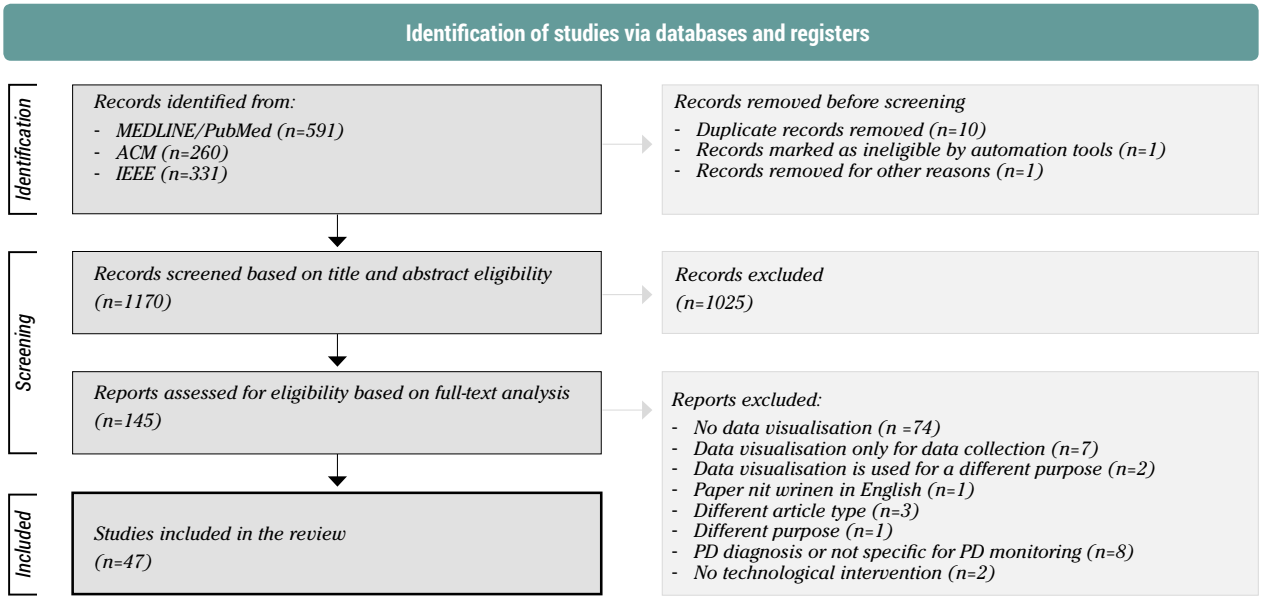

Fig 1. Prisma flow diagram.

TABLE 1. Studies' details (n = 47)

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
Dias et al., 2022 (15)	To test the usability and simplicity of the PDapp system to monitor PD patients in clinical and free-living environments and support clinical decision	On and OFF states Wrist rigidity, Bradykinesia, Gait impairment Falls Tremors	iHandU (wearable device for the wrist), Mobile application Web-based dashboard	***User validation*** ***Participants*** Neurologists assessed both interfaces.	***Visual Representation*** The ***Web-based clinician's dashboard*** is composed of an initial screen divided into four quadrants. In the first quadrant, the patient's details are displayed (photo, name, birthday, the year when symptoms started, and contacts). The second quadrant shows the medication intake for the last seven days using a line graph. Furthermore, information regarding drugs, dosage, and frequency of intake is also displayed. The third and fourth quadrants show a list of the most recent events (i.e., off-state, tremor, difficulty in walking, falls) and the name of the tests performed. On the screen showing tests' results, patient's performance is displayed as percentagens (%) of improvement, duration of the test in seconds, and the max, average and min in dg/s.
Serhani & Chao, 2013 (16)	To develop an end-to-end system for continuous monitoring of PD patients	Tremor	Sensors Accelerometer Wearable EEG monitor, ECoG	***Software development***	***Basic*** A smartphone application will be used to display customised data using a variety of formats, including tables, graphs, and reports.
Seong, Lee, & Kang, 2014 (17)	To develop a watch platform that records the data of the user's daily life activities.	User's daily life activity for diverse services	Sensors Watch	***Software development***	***Visual Representation*** A user interface displays the type and date of different events, such as movement, going out, going home, weight measure, medication intake.
Patil et al., 2022 (18)	To develop smart shoes to detect FoG and falls in PD patients	Freeze of gait Falls	Smart shoes Electromyography Pressure sensors, Gyroscope Accelerometer	***Software development***	***Conceptual*** The ***Blynk app*** displays FoG episodes using a line graph. Every time a FoG episode is identified, the app records the time of occurrence for future analysis and monitoring

TABLE 1. *(continue)*

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
Thinh, Thang & Thanh, 2017 (19)	To develop a self feeding device to support individuals with arm disability in self-feeding activities	Nutritional intake	Robot (FeedBot)	***End-users involved during design*** Patients and caregivers' opinions were taken into consideration during the design of the prototype	***Basic*** Smartphone app show the meal's data as graphs, charts or figures. The data presented regards the meal's nutritional value, favourite food, and meal time. Additionally, it is possible to include remarks and observations regarding user food habits.
Pulliam et al., 2018 (20)	To validate algorithms for continuous simultaneous monitoring of tremor, bradykinesia, and dyskinesia in the context of quantifying levodopa dose response and development of tools for quickly visualizing individualized response patterns.	Tremor, Bradykinesia, Dyskenia	Kinesia motion Sensor units Tri-axial gyroscope and accelerometer	**Software development** **Participants:** 13 PD patients ***Task:*** Six activities of daily living: brushing hair and teeth, dressing, eating, writing on a paper and using a computer, reading or watching tv, folding towels and clothes	**Visual Representation** Radar charts were used to visualize the individualised dose response for each subject across all metrics, bradykinesia score, tremor score, tremor duration, dyskinesia score, dyskinesia duration, at rest. Each axis of the chart represents one of the objective metrics, which range from 0 to 4 for the severity scores and 0 to 100 percent for the duration detected, with larger values indicative of more impairment. The two shaded areas were represented corresponding to metrics extracted from the period before (black) and after (grey) taking medication.
Synnott, Chen & Nugent, 2011 (21)	To assess if an off-the-shelf consumer technology (i.e., Nintendo Wii) provides an intuitive mean of interaction with a package capable of capturing, analyzing, and visualizing a wide range of motor and non-motor metrics	Tremor, Slowness of movement Reduce fine motor coordination	Nintendo Wii 3-axis linear accelerometer front-facing infrared camera	***Software development*** ***Participants:*** 5 healthy individuals ***Task:*** Mini-games similar to tasks carried out during a clinical assessment (e.g., Target Shooting, Target Holding, Target Following, Button Tapping (prompted), Button Tapping (unprompted), Target Sorting	***Basic*** A ***visualization engine*** which displays and summarises the relationship between metrics in a technical manner for clinicians and a non-technical manner for patients and other stakeholders.
Ho et al., 2024 (22)	To showcase the suitability and efficiency of a platform that enables the recording and uploading of gait trial data seamlessly from any location.	Gait parametrs: Stride length, Stride width, Stride time, Velocity, Cadence	2D and 3D data from a binocular 3D camera for monitoring and analysing gait parameters.	***User validation*** ***Participants:*** 122 PD patients and 224 healthy subjects ***Task:*** 8-meter walking test	***Visual Representation*** ***Clinicians' interactive dashboards*** are composed of three working areas. On the left section of the screen (1/3) is displayed the patient profile, including name, gender, birthday, diagnosis, stage of disease, and additional information In the upper right section of the screen, there is a line graphic that shows the last scores obtained on the last assessment moments in different gait parameters (i.e., stride length, time, velocity, cadence turn time). In the downright section of the screen, is shown the score obtained on the same gait parameters, together with videos of the exercises.
Rigas et al., 2009 (23)	To developed a system that monitor, assess and propose treatment plans to PwP	Tremor	Smartphone sensors Accelerometer	***Software development*** ***Participants:*** 5 health subjects (i.e., medical doctors) assessed both interfaces. ***Task:*** Subjects were equipped with the sensors and asked to simulate Parkinsonian tremors with a severity of 1 to 4.	***Basic*** ***PERFORM*** system is composed of two interfaces: The clinician interface, enables healthcare professionals to evaluate the patient's disease features, evolution over time, personalized patients' treatments and medication schedules and generate statistical information. Patient management interface, which is responsible for the identification and quantification of the patient's symptoms and the recording of other useful information related to the evaluation of the patient's status, such as patient activities.
Madani, Lohi & Lohi, 2010 (24)	To developed a system that monitor, assess and propose treatment plans to PD patients	Tremor, ON and OFF states, Drug-induced dyskinesia, Falls, Galvanic Skin Response, SpO2, Pulse rate	Sensors Accelerometers, Gyroscopes, Galvanic Skin Response, SpO2 Pulse	***Software development***	

TABLE 1. *(continue)*

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
Megalingam et al, 2014 (25)	To facilitate communication between a wearable health monitoring system and the external world with a smartphone.	Heart rate, Blood oxygen saturation, ECG, Temperature, Respiration rate, Tilt, Fall	Sensors	***User validation*** ***Participants:*** 6 subjects ***Task:*** ECG measured with sensor	***Basic*** A ***customizable application software*** will be developed which will provide specify critical limits and values beyond which an alert mechanism is triggered.
Ryder et al., 2009 (26)	To develop an application that infer user's transportation mode (walking, running or stationary)	Mobility patterns	Mobile phone sensors Accelerometer GPS	***Software development***	***Visual Representation*** A ***web-based application*** provides a daily snapshot of user's ambulatroy activity. Through this app data is available to the user, user's family, friends or caregivers. In addition a ***Daily trace calendar*** displays the user's location traces for each day in a monthly calendar.
Patel et al., 2010 (27)	To develop a longitudinal home-monitoring system of PD patients	On and OFF states Dyskinesia, Bradykinesia, Tremor	Wearable sensors Tri-axial accelerometers Video conference server	***Software development***	***Visual Representation*** ***MercuryLive, a web-application*** The platform provides access to sensor data and supports live video communication between clinicians and patients during motor exercises. A GUI displays live decimated motion signals alongside the video session to allow clinicians to view and annotate data during each remote supervised data collection session. The GUI also enables the inclusion and selection of specific daily life activities exercises (i.e., motor tasks), displaying the time spent on each task. Clinicians can also download long-term data to allow customised rigorous data analyses
Chen et al., 2010 (28)		Motion data		***Software development*** Patients' data were collected for three hours during the performance of 100 planned tasks	
Patel et al., 2011 (29)				***Software development*** ***Participants:*** 5 PD patients were recorded over a period of three days (two days in a clinical setting and one day in a home setting). ***Task:*** Two tasks from UPDRS (i.e., heel tapping with left and right leg and alternating hand movement (pronation/supination with left and right hand)	
Zhang et al, 2011 (30)	To monitor PD remotely, record and analyze functional activities, and provide accurate real-time feedback with a smartphone. Three studies were conducted.	Standing, Sitting, Lying, Walking, Sit-to-stand and stand-to-sit transitions	Three sensors Accelerometer Gyroscope	***User validation*** ***Participants:*** Study 1: n/a Study 2: n/a Study 3: 10 healthy young subjects ***Task:*** Study 1: System validation Study 2: System validation Study 3: Functional activities trials	***Basic*** ***Functional Activity Monitor system*** The smartphone stores data, analyzes data online, provides feedback to the user and update results to the health care center through either an Internet or cellular connection.
Gatsios, Rigas & Konitsiotis, 2021 (31)	To identify the core requirements of the PRIME CDSS functionally and dashboard	Tremor, Dyskinesias	Smartphone, Smartwatch, Pair of smart insoles	***End-users involved during design*** ***Participants:*** Movement disorders experts and 2 experienced software engineers ***Task:*** Expert discussion until a consensus was reached	***Conceptual*** *UR1* - Offer discrete and standardized neurologic examination documentation options *UR2* - Enable tracking of changes to neurologic examination findings or severity *UR3* - Automatically integrate patient portals and import patient-reported outcomes *UR4* - Incorporate PD-specific clinical data (neuroradiology, neurophysiology) *UR5* - Present to the clinicians similar patients' cases to the one being assessed *UR6* - Provide clinicians with suggestions based on Guidelines (MDS, NICE) to guide their diagnosis, visualizing relevant historical data, e.g. from motor fluctuations *UR7* - Show non-motor and motor symptoms in common and informative graphs, whenever possible *UR8* - Provide drill-down capabilities to enable clinicians to get insights into specific timeframes, e.g., using a calendar-like module, also supporting comparisons

Continue →

TABLE 1. *(continue)*

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
					UR9 - Present in a single view info for symptoms and medication adherence to correlate them *UR10* - Present the specific symptoms, comorbidities and timeframes of interest for each patient instead of providing standardized views *UR11* - Provide a tool with medication options based on MDS and other evidence-based clinical Guidelines to support treatment decisions *UR12* - Include drug-drug interactions, drug-gene interactions, drug-protein interactions (whenever data on genetics is available) to support prescribing. *UR13* - Include the up-to-date list of the prescribed pharmacotherapy and supporting therapy plans *UR14* - Include adherence to pharmacotherapy and supporting therapy plans. *UR15* - Enable the monitoring and evaluation of changes in the pharmacotherapy and supporting therapy plans to provide an improved treatment plan *UR16* - Provide (optionally) ecologically valid summary activity and sleep data. *UR17* - Support data sharing between clinicians *UR18* - Enable data sharing among clinicians involved in the multidisciplinary care of patients (where applicable).
Fei et al, 2020 (32)	To collect data, real-time data display, and data analysis using a wearable health monitoring system	Heart rate, Blood pressure, Step count	Wrist band with Sensors Accelerometer Gyroscope	***Software development***	***Conceptual*** ***Wearable health monitoring system*** This system includes a complete method for monitoring heart rate, real-time displaying, history data recording and transmitting important data to the mobile phone for further analysis. In addition to the heart rate monitoring, other features such as step counting, abnormal gesture detection and falling detection are also included, and users can classify abnormal gesture and trained off-line.
Pierleoni et al, 2019 (33)	To monitor and automatically evaluate PD with wearable devices to support medical evaluation using visualization and classification of data collected.	Tremor, Freeze of gait	Wrist band Accelerometer Gyroscope Magnetometer	***User validation*** ***Participants:*** 60 participants (healthy subjects and PD patients) Tremor: 40 Freezing: 10 Remote: 10 ***Task:*** Clinical assessments (Index-nose test, Timed Up and Go, transit through a narrow passage, transit through a door that end by sitting and on a chair)	***Conceptual*** The system for remote monitoring allows both the doctor and the patient to access the daily view of the patient's clinical status and the history of tremor and FoG episodes recorded during the monitoring period. In addition, it is also possible to automatically generate a spreadsheet showing the significant events of the day.
Jusufi, Nyholm & Memedi, 2014 (34)	To present interaction and visualisation approaches used to aid clinicians in the analysis of repeated measures of spirography of PD patients	Motor fluctuations between On and Off states in dyskinesia symptoms	Touch screen device	***Software development***	***Conceptual*** The overall visualization helps the clinicians discover different kinematic features of the PD patients. The two views (spiral and time series plots) are coordinated and linked, enabling the user (clinician) to explore the data in more detail. This enables the user to investigate data at specific time points in one view in context of the other.
Santos et al, 2019 (35)	To monitor gait in PD patients and assist healthcare professionals with reports of the collected data	Gait patterns	Shoe insole Sensor Vibration	***Software development***	***Conceptual*** A smartphone application with graphics and images is available for the healthcare professionals to consult the patients' history information. In the initial screen the app also informs the most frequent type of classification and the status of the evaluation of the gait training. In the history menu, the healthcare professional has the option to consult in three ways: Daily, Monthly, and Weekly.

TABLE 1. *(continue)*

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
Polychronidou et al, 2024 (36)	To present the HealtVision	Heart rate Saliva Activity Social and Psychological data	Sensor	***Software development***	***Conceptual*** Visualizations of the data collected using scatterplots, line plots, graph-based plots, among others. Also it is presented a map between different feature type and the most relevant visualization category.
Solachidis et al, 2021 (37) **Belmonte-Hernandez et al, 2019** (38)	To improve quality-of-life in Pd patients and facilitate healthcare professional in obtaining objective data regarding movement evolution	Heart rate, Steps, Motion data, User activity, Sleep analysis, Fall,	Multisensory band (bracelet) Localization Sleep Tracker, Microphone, RGB-D, Accelerometer	***Software development*** ***Longitudinal feasibility study 3 months per participant*** ***Participants:*** 30 participants (6 physiotherapists, 12 controls, 12 PD patients)	***Conceptual*** ***TENDER rehabilition tool user interface*** The main focus is personalizing services and functions to: i) Patients by providing personalized recommendations, ii) Caregivers by helping them understand patient situation and providing suggestions on care steps to take into account and information to review iii) Professionals by highlighting patient key information to have an overall picture of patient data.
Kumar et al, 2023 (39)	To monitor PD remotely with an application	Tremor, Bradykinesia, Balance	Smartphone Accelerometer Gyroscop	***Software development***	***Conceptual*** The user interface component provides a visual representation of the detected tremors, along with additional information or feedback for the user. The interface enables the user to interact with the software and review the results.
Fadhlannisa & Basari, 2020 (40)	To develop an electromyography based remote-monitoring system so	Muscle activity of Parkinson's disease patients	Sensors NodeMCU-based wireless EMG device	***Software development***	***Conceptual*** ***EMG monitoring system display interface,*** showing EMG amplitude through a line graph in the upper part of the screen, and a 2x2 table showing time and EMG value in the bottonm part of the screen. The monitoring system program can also be accessed via smartphone.
Bernardini et al., 2018 (42)	To collect motor and non-motor PD symptoms and improve communication with specialists	Apathy, Depression, Non-Movement Problems, Movement Problems, Health Status, Pain	ePROs	***Longitudinal feasibility study*** Every 2 months for 1 year ***Participants***: 10 PD patients and 7 caregivers ***Task:*** Apathy Survey, Depression Survey, Non-Movement Problems Survey, Movement Problems Survey, Parkinson's Disease Survey, Health Condition Survey, Pain Condition Survey, Caregiver Burden Survey	***Conceptual*** A ***visual characterisation of users*** is displayed using a 3x3 table with Patient ID, a qualitative assessment of scores obtained in the surveys filled in (e.g., Normal/ Warning). The warning is specific for the set of surveys filled in and is indicative of symptoms worsening (e.g., PSY Warning).
Gugliandolo, et al., 2019 (43)	To develop a system which is wearable, able to record, store, and wirelessly transmit three-axial acceleration data, and it can track the GPS position of the patient wearing it.	Tremor	Sensors Four accelerometers connected to an embedded development board	***User validation*** ***Participants:*** 2 PD patients and 1 healthy subject with 40, 62, and 54 years old, respectively ***Task:*** 1 PD patient - to hold the system in their hand, and then hold a pen; 2 PD patients - to put their hand in two positions	***Visual Representation*** A ***web app*** shows the data acquired, plotted in real-time, and some statistics. In the upper part of the screen is shown the three sensors' signals using a three-line graph. In the bottom section, the patient's current location is shown on a map, and some statistics, such as the number of hours walked and the estimated frequency of each channel is displayed.
Wagner & Ganz, 2012 (44)	To develop and test a portable and accurate gait analysis system, that enables patients to monitor their gait and track progress and improvement over time.	Gait patterns (i.e., stride time, swing time, stance time, stride time variability, step time balance)	Shoe insole Two microcontroller Android Smartphone	***Software development***	***Visual Representation*** The smartphone analyzes the raw data to produce temporal gait parameters that are displayed to the user on a graphical user interface.

TABLE 1. *(continue)*

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
Cunha et al., 2016 (45)	To present a novel portable, low-cost kinect-based system that aims to enhanced the typical patient monitoring and assessment methods used in clinical practice and research	Gait parameters	RGB-D camera (Microsoft Kinect) Two integrated software applications, KiT (KinecTracker) and KiMA (Kinect Motion Analyzer	***Software development*** ***Participants:*** Study 1: 3 PD patients treated with deep brain stimulation and 3 healthy subjects; Study 2: 4 PD patients and five non-PD patients ***Task:*** Single task performed in a hospital setting	***Visual Representation*** KiMA interface allows the storage and replay of video records of patients. KiMA also facilitates the management (creation, edition and deletion) of labels and events for the identification of movements of interest (MOIs), with this information being visually displayed above the video. Furthermore, events can be exported as segments of the original data acquisition, enabling their review on a dedicated workstation.
Lin et al., 2016 (46)	To develop an algorithm to evaluate the severity of festinating gait behaviour.	Festinating Gait	A posture monitoring vest with multiple 3-axis accelerometers	***Software development*** ***Participants:*** % healthy subjects	***Visual Representation*** A ***mobile app*** was developed so each individual can review their gaiting behaviour in the past 9 months. A three-line graph is used to display the average and stand deviation stepping frequency, ratio index, and the upper body lean forward angle
Bourazeri & Stumpf, 2018 (47)	To co-design a user interface of a self-care smart home technology toolset with people living with PD and their caregivers using the PERCEPT approach. Four workshops were conducted	Well-being and quality of life. Physical and psychological outcome	Tablet	***End-users involved during design and User validation*** ***Participants:*** 6 PD patients (first workshop), 5 afterwards; 4 PD (first workshop) 3 afterwards. Two different sessions with each group ***Task:*** 4 workshop session. Empathy probes between W1 e W2 to self-report on their daily activities	***Conceptual*** Tablet interface focusing on different tasks such as set-up a profile, a life plan, sharing of their data with others, and how to monitor their life plan.
Zhang et al, 2020 (48)	To assess the first smartphone-based system to detect drug effectiveness among PD patients in daily life	Talking, Walking, Standing Symptom severity	Smartphone Microphone Accelerometer, Gyroscope	***Longitudinal feasibility study*** 6 months ***Participants:*** 81 PD patients ***Tasks***: Voice, walk, and standing activity	***Basic*** A feedback report is provided.
Lennon et al, 2015 (49)	To remotely monitor dyskinesia in PD remotely	Dyskinesia, Tremor	Sensors Accelerometer Gyroscope Smartphone	***Software development***	***Basic*** The data collected is processed and available for evaluation by a physician to help monitor dyskinesia severity.
Pereira et al, 2015 (50)	To facilitate comunication between patients and healthcare professionals with an application to monitor PD in free-living.	Medication and personal notes for PD Healthcare professional can prescribe mediciation plans and notes	Mobile application	***End-users involved during design*** ***Participants:*** 36 participants (11 PD patients, 11 caregivers, 14 healthcare professionals) ***Task:*** Fill in a survey	***Basic*** PD patients can visualize their personal notes, medication and receive alerts. Healthcare professionals can visualize patient's notes, prescribed medical plans and exercises.
Branco et al, 2019 (51)	To design a web-platform containing personalized reports of inertial sensor data. Two studies were conducted	Physical activity, Energy spent, Sleep analysis	Wrist band Inertial sensor accelerometer	***End-users involved during design*** ***User validation*** ***Participants:*** Study 1: 5 participants (1 neurologist, 2 physiotherapists, 2 nurses); Study 2: 25 particiopants (22 PD patients, 4 healthcare professionals) ***Tasks:*** Study 1: focus group and a design workshop; Study 2: PD patients used the device during 3 or 7 days, 4 healthcare professionals used DataPark	***Visual Representation*** Each report is composed of a set of charts, tables, and measures that give a processed analysis of the raw data. The information shown is about physical activity, energy spent, and sleep. They used different types of views for data, for example, by day, week, or period of the day. If needed, clinicians can adjust each report according to the patients or the type of analysis they want to see or discuss.

TABLE 1. *(continue)*

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
Dubey et al., 2015 (52)	To assess the performance of EchoWear, a smart-watch-based system, to remotely monitor speech and voice exercise	Speech/ dysarthria	Smartwatch Microphone	***Software development*** ***Participants:*** 3 PD patients and 3 healthy subjects ***Task:*** Three speech tasks. *Task 1* - vowel prolongation task, *Task 2* and Task 3 were developed to record high and low pitches	***Conceptual*** The system uses large amounts of speech quality metrics (SQMs) computed over time, including average loudness level in dB (Phon) and average fundamental frequency (Hz) to provide automatic health reports to the speech-language pathologist and/or participants, using for instance bar charts.
McNaney et al, 2022 (53)	To explore que perceptions of PD patients and their caregivers about sensors and how data collected from these devices can be visualized. Two studies were conducted.	Activity, Temperature, Parkinson's symptoms	Sensors Accelerometer Environmental sensors Silhouette video Cameras Smart home sensors Mechanical flow sensors Wearable device	***End-users involved during design*** ***Participants:*** *Study 1:* 12 participants (6 PD patients and 6 caregivers); *Study 2:* 8 participants (4 PD patients 4 and caregivers) ***Task:*** *Study 1:* 2-hour session at a smart home equipped with sensors to complete a set of activities (meal preparation, cleaning, sleep-related activity, washing up and resting; *Study 2:* 2-hour workshop to show garaphical data visualization of the sensors 'outputs.	***Conceptual*** From the workshop discussion around data visualization from sensors, participants reflected about personal data opportunities for data usage, trust and transparency, data misued, and for-profit data.
McNaney et al, 2015 (54)	To develop and evaluate LApp, an application for Google Glass to help PD patients monitor their speech volume and cue themselves to speak louder when necessary. Three studies were conducted.	Vocal volume	LApp on Google Glass	***End-users involved during design*** ***User validation*** ***Participants:*** *Study 1:* 7 PD patients; *Study 2:* 8 Healthy subjects; *Study 3:* 6 PD patients ***Task:*** *Study 1:* Exploratory design workshop; *Study 2:* Test the application in a 30-minute session; *Study 3:* 3 days usage of LApp on Glass to explore PwD experiences using the app.	***Conceptual*** During the workshops different types of cues were suggested by participants (visual, haptic and auditory). There was some disagreement in relation to what would be preferred, with some suggesting audible cues that only they could hear, and others preferring visual or haptic cues they could respond to. Participants came to an agreement that cue preferences depended on context, but all felt comfortable with the idea of using a 'traffic light' style visual cue shown directly on Google Glass.
Chuang et al, 2010 (55)	To promote patient-centered healthcare and self-management with monitoring devices.	Blood pressure, Weight	Blood pressure monitor, Digital weight scale	***Software development***	***Visual Representation*** The system can display graphs that show the gradual progression of the measurements over weeks, months or years. The patient can identify whether the measurements are normal by the colors of the graph's points (green means normal, yellow means warning, red means attention is required). If the patient clicks on a point on the graph, the actual measurement and an "analysis message" appears in the left column.
Zhu et al., 2016 (56)	To assess the feasibility of computer vision-based gait analysis system	Gait analysis	Camera of a mobile phone	***Longitudinal feasibility study*** 2 weeks ***Participants:*** 55 elderly subjects, 44 PD patients and 11 healthy controls ***Task:*** Walking from left to right, turning around at the end and walking back	***Conceptual*** To provide information to doctors or clinicians, the system is able output the subject's basic statistical information, including mean, coefficient of variation, and standard deviation of left and right stride lengths and times.
McNaney et al., 2016 (57)	To evaluate how the provision of feedback, using apeeching, was valued by PD patients.	Speech Articulation, Volume Rate Pitch variability	Mobile phone	***Longitudinal feasibility study*** 1 week ***Participants:*** 6 PD patients [61 - 74 years] ***Task:*** Patients' speech samples (e.g., reading 10 single words and reading sentences, describing a picture or answering an open question. Finally, there is a combination of reading words and free speech)	***Visual Representation*** The ***Speeching app*** enables users to receive feedback on their speech and allows for the self-directed practice of speech issues common to PD. Patients are provided with a graph of their Ease of Listening (EOL) score over time, the EOL score of the sample they have just submitted, along with its volume, rate and pitch scores. Users are advised that both volume and pitch scores should fall within 50 and 90, while scores for rate should be between 40-60.

TABLE 1. *(continue)*

Paper reference	Aim and Context	Health-related outcomes	Technology employed	End-users involvement and methods	Dashboard / data visualization description
Lipsmeier, Florian, et al, 2018 (58)	To determined the feasibilty, reability, and validity of digital biomarkers during a 6-month clinical trial of individuals with PD patients. Two studies were conducted	Tremor Bradykinesia Rigidity/postural instability	Smartphone app (Roche PD mobile application) IMU sensor (accelerometer, gyroscope, magnetometer) Voice recorder	***Longitudinal feasibility study*** *Study 1:* 6 month *Study 2:* 6-week observational ***Participants:*** *Study 1:* 43 PD patients; *Study 2:* 35 Healthy match controls ***Tasks:*** 6 active tests + passive monitoring (walking, s2s, walking)	***Conceptual*** An image of the ***Roche PD*** mobile application shows that users have access to overall progress of the completed days of active testing and the amount of hour. The overall progress is displayed in a donut chart.
Barros et al, 2013 (59)	To design and evaluate a PD self-management approach with four smartphone applications.	Personal information, Blood type, Medication, Medical condition Adhrence and prescription list	4 Smartphone applications	***End-users involved during design*** ***User validation:*** *Interviews* – 5 PD patients, 1 informal caregiver, 1 physical therapist; *Scoping session* – 3 PD patients, 3 informal caregivers; *Focus group* – 2 PD patients, 2 informal caregivers; *User cases* – 3 medical doctors; *Second Part* – Software development; *Third Part* – User validation with usability test	***Conceptual*** ***REMPARK system*** is composed of different applications: medication, appointments, my day (disease status/symptoms), my data (personal and health information), messaging, calling, emergency call, contacts, two cueing controllers to improve users's gait, and medical questionnaires In my day app, a 24h clock graph is displayed showing freeze of gait, festination, diskenesia and failure in medication intake using flags.
Isaacson et al, 2019 (60)	To investigate whether using Kinesia 360 at home could improve motor symptom management in PD patients starting transdermal dopamine agonist rogigotine	Tremor Slowness, Dyskinesia Walking severity	Kinesia 360 mobile application motion sensors Kinesia ONE mobile application finger or heel motion sensor to colllect data	***Longitudinal feasibility study*** 12 week ***Participants:*** 39 PD patients (20 control group and 19 experimental group) ***Tasks:*** *Experimental group:* used Kinesia 360 to perform healh related assements; *Control group:* did not use kinesia 360 and were only provided with standard care. Both Groups used kinesia ONE at day 1 and week 12 to measure motor assessment performance during specific motor tasks	***Conceptual*** ***Kinesia 360 smartphone app*** provides data reports for patients about the health-related outcomes. For walking severity display a traffic-light analogy is used.
Belmonte-Hernandez et al, 2022 (61)	To develop a system to collect raw information. Three studies were planned (two were conducted).	Sleep Daily activities Steps Freezing, Bradykinesia Gait festination Walking Balance	Smartwatch, Door sensor Smartphone, Depth Sensor	***User validation*** ***Participants:*** PD patients, caregivers, healthcare professionals ***Task:*** *Study 1:* Use web and mobile application; *Study 2:* Use different devices and configurations; *Study 3:* Use all the available features for the platform	***Visual Representation*** ***ProCare4Life system Web Interface*** to be used by healthcare professionals to manage and monitor their patients. It has a dashboard available with charts and metrics. A mobile application enables patients to access and manage their data in the PROCare4Life platform. Smart TV Cognitive Gaming Tool provide cognitive games and questions to create an experimental screening tool that will be used to assess the cognitive abilities of patients.

Legend: ***ECG*** *– Electrocardiogram;* ***EcoG*** *– Electrocorticography;* ***EEG*** *– Electroencephalography;* ***EMG*** *- Electromyography;* ***FoG*** *– Freezing of Gait,* ***GUI*** *– Graphical User Interface;* ***PD*** *– Parkinson's Disease;* ***SpO2*** *- Peripheral capillary oxygen saturation;* ***UPDRS*** *- Unified Parkinson's Disease Rating Scale.*

TECHNOLOGIES AND DEVICES FOR PD MONITORING

Patients' data were collected using various technologies, including sensors directly attached to the participant's body (16, 20, 24, 25, 27-30, 36, 40, 43, 48, 49, 53, 60), integrated into smartphones (23,26,39), or incorporated into accessories, such as wristbands (15, 17, 32, 33, 37, 38, 51, 61), smart shoes (18), smart glasses (54), shoe insoles (31, 35, 44), or clothing (41, 46).

Other types of devices used for data collection included a blood pressure monitor and a digital balance (55), gaming consoles (i.e., Nintendo Wii) (21), tablets (34, 47), video cameras (22, 45, 56) voice recorders (52, 57), and mobile applications (50, 58, 59).

Additionally, one study employed a robot to assist in feeding patients with motor impairments (19), and another utilized ePROs for data collection (42).

HEALTH-RELATED OUTCOMES

As a central criteria of the present review, all studies included focused on technologies that enable the monitoring of PD patients. Among the health-related outcomes, motor symptoms of PD were the primary focus in 39 out of 47 studies. The predominant motor symptoms analysed were tremor (15, 16, 20, 21, 23, 24, 27, 31, 33, 39, 41, 43, 49, 50, 60), bradykinesia (15, 20, 21, 27, 38, 39, 49, 58), dyskinesia (20, 24, 27, 31, 34, 49, 60), wrist rigidity (15), fine motor coordination (21), tilt (25), and balance (38, 39, 58). Additionally, other studies examined motor fluctuations between the On and Off states (15, 24, 27, 34) associated with the intake of levodopa (20).

Distinctive features of PD associated with impaired walking capacity were also analysed (15), including FoG (18, 33, 38), falls (15, 18, 24, 25, 37), and gait festination (38, 46). Other studies focus on speech impairments, including dysarthria (52), variations of the vocal volume (54, 57), articulation, and rate and pitch variability (57).

Another group of studies opted to focus not on clinical symptoms but rather on motor metrics/gait parameters, including but not limited to stride length, stride width, stride time, velocity, cadence swing time, step count (22, 26, 28, 29, 32, 35, 37, 38, 44, 45, 48, 56), physical activity (51) and user's capacity to execute motor tasks (30, 48), including standing, sitting, lying, and walking as mean to assess and monitor the progression of PD motor symptoms.

Physiological data considered in some of the studies included were: heart rate (25, 32, 36, 37), galvanic skin response (24), blood pressure (32, 33), blood oxygen saturation (24, 25), pulse rate (24), EEG (16) and ECoG (25), EMG (40), temperature (25, 53), respiratory rate (25), saliva (36), and sleep parameters (37, 38, 51).

Studies focused on non-motor aspects were less frequent (8 out of 47) and primarily investigated nutritional intake and patients' capacity to feed themselves (19), medication intake (50, 59), capacity to perform daily life activities (17, 38), health status, including pain, depression and apathy (42), social and psychological health (36), well-being and quality of life (47).

DATA VISUALIZATION

When it comes to providing end-users with feedback on the collected data, three levels of data representation were identified: basic, conceptual, and visual representation. Among the studies included, 10 articles were classified as offering a basic description of how data is visually presented to end-users. In these cases, the studies only mentioned the format of feedback provided to end-users without delving into specifics. Of these, two studies simply mentioned that some form of feedback is provided to end-users without providing further details (49, 50). One study specified that a report is provided to end-users (48), while four studies utilized a customizable application/interface (21, 23-25). Additionally, three studies indicated that feedback is delivered through a smartphone application (30), with two of them mentioning that tables, graphs, charts, reports, and figures can be used for visually displaying the data (16, 19).

On the other hand, 21 articles were classified as describing the type of data displayed without a dashboard having been developed (i.e., conceptual). Among these, 10 studies (31-33, 37-39, 41, 47, 53, 56) just mentioned the type of data that ideally would be reported to end-users. For more details on the data considered in these studies, see Table 1. Studies' details (n=47). The remaining 11 studies provide a more detailed description of how data will be presented. For instance, Jusufi, Nyholm and Memedi (34) considered using spiral and time series plots to visually represent motor fluctuations over time. Tables (35, 42) and donut charts (58) were mentioned in three studies as a possible way to visually display data when patients performed motor tasks and the results obtained on those tasks. Line and graph-based plots were mentioned to display physiological data such as EMG (40), and heart rate (36), respectively. Patil et al. (18) mentioned using line graphs and dates to report FoG episodes, while Barros et al. (59) used 24-hour clock graphs with different time flags to report the occurrence of FoG, festination and dyskinesia episodes and patients' compliance with medication schedules. Finally, in studies focused on speech impairments associated with PD, bar charts (52) and a traffic-light-based graph (54) were presented as suitable forms to represent speech quality and volume, respectively. Isaacson et al., (60) also propose the use of traffic-light-based graphs to visually display gait impairment.

Finally, more complex and detailed forms of data visualization (i.e., dashboards) were identified in 16 of the studies included. For instance, in two of these studies, specific sections of the dashboard were reserved for patient's personal information, such as name, photo, birthday, year of symptoms onset, and contacts (15,22). Furthermore, information regarding medication, dosage and frequency was also considered

relevant to be present in clinical dashboards aiming at monitoring PD patients, with this data presented either in list format (17), or alongside the patient's personal information (15).

To provide feedback on the occurrence of PD-related symptoms such as tremors, difficulty in walking, falls, and OFF states, lists with dates and time of the event were used (15). Improvements in PD-related symptoms were represented in three studies using percentages (15), line graphics (22) or radar charts where the severity of symptoms (e.g., tremor duration, dyskinesia) before and after medication intake was simultaneously displayed (20).

Gait behaviour (e.g., step frequency) and motor activity metrics such as stance time, swing trace, and step time balance were displayed using line bars (46) or percentages (44), respectively. Additionally, in Branco et al., (51) visualization formats such as charts and tables were identified as suitable formats to display patients' information regarding physical activity, energy spent and sleep.

Regarding video platforms, five studies focused on systems that enable clinicians to watch patients performing motor activities online (27–29) or offline (22, 45), alongside the metrics and results obtained in the motor tests and information if the patient was in the ON or OFF state while performing the tests (22). Furthermore, these platforms enable clinicians to take notes and create and edit labels to identify movements of interest (27–29, 45).

Other data considered in the dashboards analyzed included giving feedback on user location traces using maps (26, 43) or by showing events of interest in a list format (e.g., go home) (17). One dashboard also presented physiological using a three-colour graphic, where green is indicative of levels within normal parameters, yellow means caution, and red is indicative that professional assistance should be sought (55). Dashboards dedicated to reporting speech metrics used circular graphs showing the score obtained in each metric as a percentage using Arabic numerals (57). Finally, in one study (61), while a screenshot of a dashboard is provided, the low image quality couple with the lack of description regarding the data and visualization techniques used, renders it challenging to analyse the depicted elements thoroughly.

DESIGN AND VALIDATION OF CLINICAL DASHBOARDS

Out of the 47 studies included in this review, only 22 studies include stakeholders (i.e., health professionals, PD patients, caregivers) and/or healthy subjects in the design process clinical dashboards and validation of the system developed.

User validation was reported in 14 studies. Of those, in seven studies, participants were invited to test the feasibility of the system for a single session (15, 22, 25, 30, 33, 43, 61), while in another seven studies, participants were asked to use the system for longer periods (38, 48, 56, 58, 60), ranging from one-week (57) to every two months for one year (42).

Regarding the design process of the clinical dashboards, only eight studies reported following a co-design/participatory design approach during the development of the clinical dashboard for monitoring PD patients. Nonetheless, the degree of end-user involvement also varied across studies. For instance, in Thinh, Thang & Thanh, (19) it is reported that "patients and caregivers' opinions were taken into consideration during the design of the prototype". However, it does not mention how these opinions were collected or how they contributed to the design of the final dashboard. In Pereira et al., (50) a survey was filled out by 36 participants, including PD patients, caregivers and health professionals, aiming to characterize participants' profiles and identify the needs and functionalities they identified as relevant to have in the app for monitoring of PD. Other forms of end-user involvement in the design process of clinical dashboards for PD monitoring were the conduction of focus groups (51) and Delphi panels (31) bringing together experts in PD and software development engineering. Finally, the conduction of workshops (47, 51, 53, 54) and interviews (59) aiming to identify the needs and elicit hypothetical scenarios that could support the design of clinical dashboards were also reported in five studies.

DISCUSSION

In this study, we conducted a systematic review of the literature to identify, analyse, and synthesise the available research dedicated to the development of data visualisation techniques and dashboards for PD monitoring.

Regarding technologies and devices used for PD monitoring, our findings revealed that sensors embedded in various devices are currently a prevailing

trend for data collection (present in 33 out of 47 studies included). Through the use of these devices, data collection can be done in a non-invasive manner, either in an active way, requiring patient intervention (e.g., performing tasks like finger tapping) (62), or passively, utilizing only the device (e.g., ambient sensors) (63). Nonetheless, scientific literature indicates that sensors that enable data collection in a passive way are more easily accepted by end-users (3), and so future research would probably evolve around the development of this type of sensor.

Another trend identified in our study was the focus on developing technology that primarily collects and analyses data related to PD motor symptoms. Parkinson's Disease is characterized by the presence of both motor and non-motor (e.g., cognitive) impairments. However, most studies included in our review (39 out of 47 studies) focused on PD motor symptoms such as tremors, bradykinesia and dyskinesia, among others. Only a small portion of the studies analysed (8 out of 47 studies) focused on PD non-motor symptoms, such as depression, apathy, quality of life and well-being. This finding may reflect a preference for parameters that are the most easily measurable. However, this finding also highlights that there are still plenty of opportunities to be explored in other areas of research, including daily living (34, 39), which are also heavily dependent on cognitive health and may have a direct impact on people's quality of life (64).

In the clinical context, dashboards can play a significant role in facilitating the continuous monitoring of changes in a patient's health status (65,66). However, at a moment where digital devices generate vast amounts of data, the challenge resides in how this data can be digested to facilitate interpretation and practical use in clinical settings (12).

While the concept of data visualisation was ubiquitous across all articles, the extent of its implementation and the level of detail in the techniques employed varied greatly among the studies analysed, with only a small portion (16 out of 47) of the studies included focused on studying and exploring the best ways to consolidate the information collected using an organized visual representation to make interpretation of clinical data simpler and more intuitive (1).

Furthermore, when considering the involvement of end-users in identifying relevant data and determining the best way to represent them, even fewer studies focus on this aspect (6 out of 47). The engagement of end-users, such as in co-design studies, is a crucial component that should not be overlooked, as it impacts technology usage (4). For this reason, involving stakeholders is a fundamental step in defining relevant data and designing platforms and their visualisation formats (67). This is especially true in the healthcare field, where resources are limited and health professionals are in constant demand (68). Therefore, and although the adoption of technology in clinical practice is not always an easy task, it is extremely relevant to improve how data are presented to healthcare professionals to enhance technology's value (68) and optimize clinical decision processes.

LIMITATIONS

The study's results should be interpreted considering some limitations. Firstly, the strategy employed to identify publications, including the keywords used to filter titles/abstracts and the selected collections, may impact the findings. Also, we did not proceed with the analysis of secondary references (e.g., studies included in systematic reviews), which might have excluded potentially relevant papers. Nonetheless, the present results were obtained based on articles identified through searches in three different databases, with some of them highly specialized in software development (i.e., ACM and IEEE). Furthermore, the fact that terms such as monitoring, assessment, evaluation and screening are sometimes used interchangeably in the papers analysed could introduce subjectivity to eligibility criteria and data extraction.

CONCLUSIONS

This study aimed to analyse the available literature on clinical dashboards to monitor PD. Conceptual and dashboards are the predominant visual representations employed. Nevertheless, few studies include end-users during the design process of their systems and visualization platforms, which represents a major shortcoming. Moreover, regarding the data collected and used to populate these dashboards, there is a focus on PD motor symptoms that reflect their importance in disease progression monitoring. This emphasis limits the exploration of other potentially relevant activities that may directly correlate with disease symptoms and is thus relevant to be included in the dashboards aiming to monitor PD patients.

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DECLARATIONS OF INTEREST STATEMENT
The authors report no conflict of interest.

SUPPORTING INFORMATION CAPTIONS
S1 Table. PRISMA 2020 Checklist
S2 Table. Electronic databases and search strategies
S1 File. PROSPERO Protocol

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