

# Supporting Non-Communicable Disease Patients in Time of The Covid-19 Pandemic: From Motivating Them to Qualifying the Role of Their Caregivers

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## Abstract

Evidence collected globally during the pandemic show that Covid-19 has had a significant impact on patients suffering from non-communicable diseases (NCDs). Indeed, oncological and chronic patients have been left almost alone for several months, especially during the first wave of the pandemic.

At the European level, the hope is that the measures adopted thanks to the Next Generation EU Fund [1] can have, in the shortest period possible, a significant impact towards more resilient healthcare systems in each Member State, in which the issue of health acts as a key element within their National Resilience and Recovery Plans (NRRPs). In addition to this, it is extremely essential to act on two sides: to motivate patients to not neglect their treatment path, and to support as much as possible the ones who informally help them in the shadow. In fact, behind every sick person there is often a caregiver, for many of whom every day the work of care takes up almost all of their daily time, with considerable expenditure of physical and mental energy.

What is the situation of caregivers across Europe? While challenges faced by patients are a frequently discussed topic, not much is known about the issues caregivers face daily. To shed light on the latter in Italy has been a civic survey carried out along 2020 by the Italian NGO Cittadinanzattiva [2], engaged also at the European level in order to motivate patients and, as an Ambassador of the EU Pillar of Social Rights [3], committed with EU institutions to implement the 20 principles of the Pillar for the benefit of both patients and their caregivers.

**Keywords:** caregivers; non-communicable diseases (ncds); chronic patients; european union; patients' rights; civic participation; patients' advocacy groups (pags)

## Introduction

The population of elderly people aged 65 years or more will increase from 87.5 million in 2010 to 152.6 million in 2060 in the European Union. Indeed, in the EU countries, on average 3–4% of the people aged over 65 are provided with long-term institutional care [4]. This demographic trend shows a dynamic increase in demand for services of long-term care, mainly concerning a growth in the number of the elderly requiring care in their homes. In this sense, community care has become a prominent EU priority in the last few years, as also confirmed by the Horizon 2020 “Call on better health and care, economic growth and sustainable health systems” [5], and

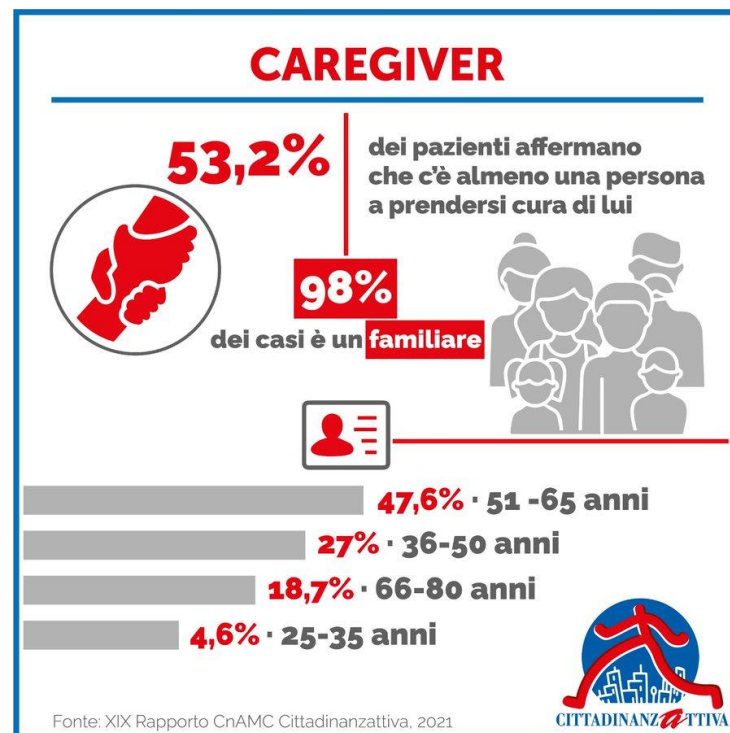
the shift towards home-based care is seen as a practical measure to contain the costs of services while supporting widespread preferences among older people. All of this puts more and more pressure on informal carers who in most European countries already provide a large part of long-term care for dependent people with disabilities, chronic or degenerative and rare diseases. In fact, at different stages of the disease, caregivers perform different tasks: they collaborate in the assistance during hospitalization, discuss with the doctors, deal with the various bureaucratic procedures, and take care of the family. They interact with the general practitioner and the social-health network and collaborate in daily nutrition, they help with personal hygiene, mobility and facilitate family and social relationships. The consequences of

this kind of work often include lack of rest, damage to health, reduction/loss of employment, poverty, inability to accrue a pension, lack of time for oneself, isolation, and stress. What is worse is that caregivers are usually alone in facing a huge number of obstacles in their daily life for a period of time of which they do not know neither the duration nor the end since the timing of caregiving may vary from a few years to more than 30 years. Most times they also face the difficult situation of managing not only their own loved one, but the entire complex health, family, social and bureaucratic situation. They care seven days a week and they don't have vacations. Their daily routine foresees commitment of 4/6 hours of direct work and 10 hours of indirect work.

Nonetheless, their role is strategic because it can impact on the person's adaptation to the new condition of illness, promoting a better quality of life for them, while at the same time performing an important welfare action instead of the institutions. However, in all their tasks, caregivers are forced to cope with many fights, such as the slowness and the fragmented responses of the social-health system, the bureaucracy, the physical and cultural barriers, and this happens in total isolation without an accompanying person.

Especially nowadays, with the Covid-19 pandemic still present, the provision of complex formal and informal care and the need to provide adequate care to these vulnerable older adults, who have experienced even more complex situations, constitute a great challenge facing our society on many levels. For instance, in Italy, the XIX National Report on Chronic Policies entitled *"The care that (still) isn't there"* [6], presented in December 2021 and realized by Cittadinanzattiva with the involvement of 64 associations of patients with chronic and rare diseases belonging to the

National Coordination of Chronic Patients Associations (CnAMC) [7] and of 3000 patients circa, has thoroughly highlighted the difficult situation faced by both patients and their caregivers. Regarding chronic and non-communicable disease patients, especially in the first wave of the Covid-19 pandemic (first half of 2020), they have been left somewhat alone for months, suffering for social distance and lockdown to avoid getting the virus, while still requiring constant doctor visits, checkups, follow-ups, prescription refills, medicines, and routine care. According to the Report mentioned above, one patient out of two, at the beginning of 2022, still states that the pandemic has increased the criticality of access to diagnosis and treatment for their diseases. Postponements and delays continue to affect specialist and diagnostic visits, and there are increasing difficulties in activating integrated home care and in obtaining recognition of disability or handicap. On the positive side, things are going better on the prevention front, thanks to the recovery of some delays in scheduled screenings and ordinary vaccinations. However, on the negative side, private costs are increasing for one out of two patients and one out of five has been forced to give up treatment for economic reasons. Together with the difficulties and requests of citizens affected by chronic and rare diseases, there are those of family caregivers - more than seven million in Italy - who are asking for less bureaucracy and more protection at work and, for the youngest, in their studies. On this last note, concerning age, according to the Report, 47.6% of caregivers fall into the 51-65 age bracket, 27% in the 36-50 years category, 18.7% in the 66-80 years one, and 4.6% are between 25-35 years of age, showing how the work of caregiving has no age and may impact on each category of individuals.



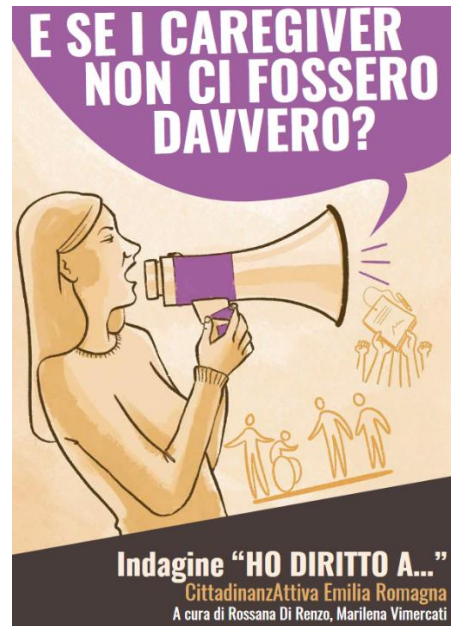
**Figure 1:** Infographic representing in Italy some of the data which emerged from Cittadinanzattiva's XIX National Report on Chronic Policies entitled *"The care that (still) isn't there"*, presented in December 2021.

In Italy, caregivers constitute a real army of invisible people which support the welfare system by caring for ill patients without any remuneration. On average, 17.4% of the population, over 8.5 million people, are caregivers. As mentioned previously, often these people are themselves elderly, like the family members they assist, but this is not always the case: more than 390

thousand are young caregivers who are between 15 and 24 years old: young people who regularly take care of a family member, devoting time, energy, balance and well-being to the family [8]. To address the huge burden faced by informal caregivers, Cittadinanzattiva Emilia-Romagna [9] realized the civic campaign *"I have the right to..."* [10] with the objective to ask for more

rights, more health protection, and a better quality of life for caregivers. 200 caregivers have participated to the campaign by sending their personal stories, which have been analyzed in the report titled “*What if caregivers did not really exist?*” [11]. At the same time, across Europe, the “*This is Living*” campaign [12], developed by Boehringer Ingelheim Pharmaceuticals Inc.

[13] and to which Cittadinanzattiva, through its European branch Active Citizenship Network [14], has been actively contributing, has been showing its support on the pursuit of health and wellness in any shape by producing useful resources and materials to meet the needs of patients suffering from non-communicable diseases and chronic conditions.

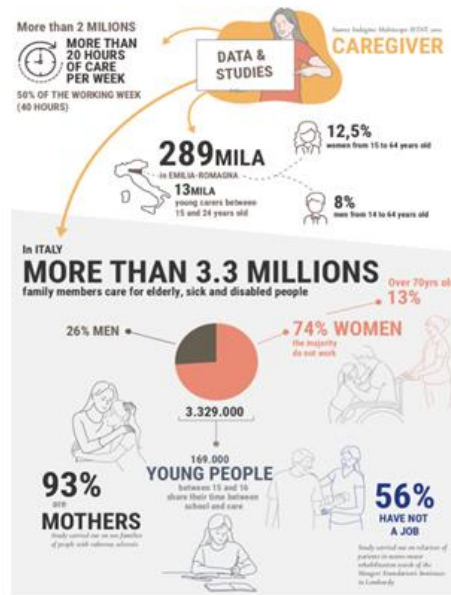


**Figure 2:** Cover of Cittadinanzattiva-Emilia Romagna’s Report titled “*What if caregivers did not really exist?*”, part of the civic campaign “*I have the right to...*”.

### Qualifying the role of caregivers in the Italian context: “I have the right to...” campaign

The civic campaign “*I have the right to...*”, launched online in early January 2020, was promoted at the national level by Cittadinanzattiva Emilia-Romagna, together with the following patient advocacy groups (PAGs): AMICI ONLUS – National Association of Chronic Intestinal Diseases [15]; ANTR - National Association of Kidney Transplants [16]; ARAD - Association for Research and Care of Dementia [17]; PARKLINK - Patients and Caregivers Committee of Bologna; CFU - Italy OdV [18]; FAIS - Federation of Associations of Incontinents and Ostomates [19]; Parkinson's Group Carpi OdV [20]; RESPIRO LIBERO – Association for the quality of life of children and allergic children [21]; UILDM - Section of “Carlo and

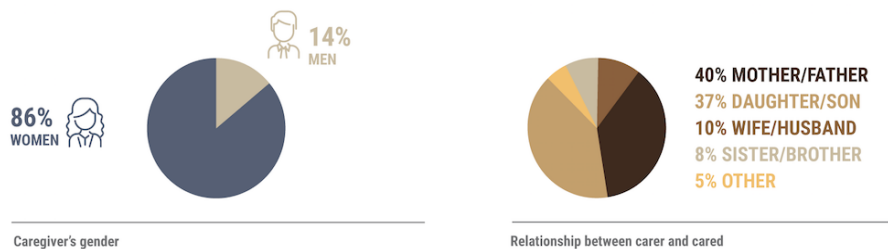
Innocente Leoni” Bologna [22], which are all part of the Regional Coordination of Associations of Chronic and Rare patients (CrAMCR) [23]. The campaign aimed at giving voice to people who life has hit hard and who have not been given discounts, creating a virtual space so that their stories would enter our daily lives and be shared with the community. It has seen the adhesion of 200 citizens who have shared their experience by accessing the webpage dedicated. The tool, used to collect and analyze narratives, was that of Narrative Medicine. The stories arrived in less than a month, confirming how much the theme of caregiving is relevant: all of them in a few lines or in intense pages have allowed to enter and understand their daily lives in terms of hardships but also of small joyful moments, and especially their requests for a recognition of their role.



**Figure 3:** Infographic representing some of the data which emerged from Cittadinanzattiva-Emilia Romagna’s Report titled “What if caregivers did not really exist?”, part of the civic campaign “I have the right to...”.

The stories collected underlined the essentiality of caregivers, generating the question: “What if caregivers weren’t really there? Who would do the work of “caring”?”. From this question has emerged the drafting, in November 2020, of the report titled “What if caregivers did not really exist?”, which shows the results of a qualitative analysis of the narratives sent by family caregivers to the campaign. The report is addressed, in particular, to politicians, institutions, professional associations, trade unions, citizens and at a cooperative and collaborative community, because it is time for everyone to do their part. The report is structured in two parts: the first part is dedicated to the exploration of the caregiving phenomenon with particular attention to the Italian context; the second part reports the results of the “I have the right to...” campaign of Cittadinanzattiva Emilia-Romagna. Since the best way for people to discover the stories was through the voice of caregivers

themselves, the report is completed by an appendix in which 10 podcasts are presented that recount 10 rights denied to caregivers [24], chosen among the testimonies received during the campaign. The first picture which emerges from the report shows how, of the 200 testimonies collected, most of them were women’s voices (86%): mothers, daughters, sisters, wives/partners who for more or less years have been taking care of a loved one with sometimes penalizing consequences on their work, but also on the side of overall family management. The few men (14%) who participated also shared their stories as carers of their wife, child or elderly parent, highlighting how carers can be men too and how pain, understanding, sensitivity and love are also emotions that men experience, an issue frequently underrated.



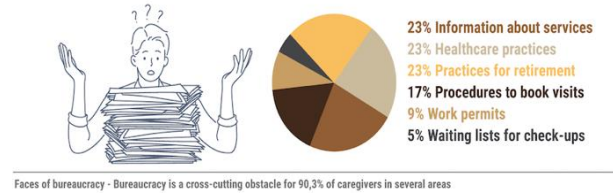
**Figure 4:** Graph representing the results of the qualitative analysis conducted on the narratives sent by family caregivers to Cittadinanzattiva-Emilia Romagna’s civic campaign “I have the right to...”.

Most of all, the report underlines how for 90.8% of caregivers, bureaucracy is "a mountain on their shoulders" representing an obstacle in the different areas in which they interact. Often the abundance of measures produced by the legislature, the bureaucratic slowness, and the lack of coordination between administrative bodies causes for the caregiver to find himself in a

labyrinth from which he often comes out defeated. As a matter of fact, rather than economic support, they ask for functioning services such as assistance in everyday life (64%), proper information (25%) guidance on the practices to be followed and training in order to be qualified to fulfill their role (11%).



**Figure 5:** Graph representing the results of the qualitative analysis conducted on the narratives sent by family caregivers to Cittadinanzattiva-Emilia Romagna’s civic campaign “I have the right to...”.



**Figure 6:** Graph representing the results of the qualitative analysis conducted on the narratives sent by family caregivers to Cittadinanzattiva-Emilia Romagna’s civic campaign “I have the right to...”.

Regarding legal and economic recognition of caring, 7% of caregivers request recognition of their role as real work, demanding primarily legitimacy of their pension rights and, for those who have a job, asking for benefits and opportunities to reconcile work time and care time. In this

framework, 42% ask for pension, 34% for economic contribution, 24% demands benefits for employment, and 28.5% of caregivers ask for quality of life/wellbeing. Important to note is also that 15.4% simply ask for the application of laws in force, such as the National Chronicity Policy Plan [25].



**Figure 7:** Graph representing the results of the qualitative analysis conducted on the narratives sent by family caregivers to Cittadinanzattiva-Emilia Romagna’s civic campaign “I have the right to...”.

As far as it regards the future, 14.1% of carers worry about them getting older and not being able to care for their loved ones as much as before. Young carers are instead often afraid of not having a future because forced to dedicate their entire time to caring for their loved ones, and frequently ask to be treated the same as working students.

**Towards the institutional recognition of the role of caregivers**

The data reported above are astonishing if we think that they come from an Italian Region which, on the topic of caregivers, is probably more advanced than others, as demonstrated by the 2014 Regional Law on the recognition of the role of caregivers [26]. The accepted Law defines and recognizes the family caregiver who voluntarily and consciously assumes tasks of assistance and care and lists the interventions in favor of the family caregiver by the Region. With this, the Emilia-Romagna Region recognizes and promotes, as part of welfare policies, family care and solidarity as social goods, identifying family caregivers as essential resources to the network of services, which at the same time need support, qualification initiatives, sharing of care responsibilities, and involvement in the construction and management of the individualized care [27]. More

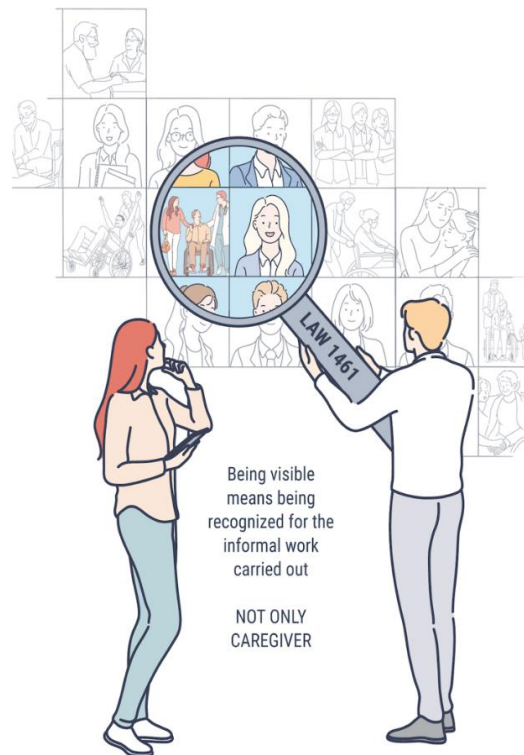
recently, at the end of 2021, the Emilia-Romagna Region has developed the web portal "Caregiver" [28], which aims to support family caregivers and make their life easier, by offering them a clear tool which informs them about their rights, all the services and opportunities available for them and associations dedicated to them in the area [29].

Despite the Region has long been committed to the qualification and empowerment of the figure of the caregiver, much remains to be done at the national level.

As a matter of fact, in Italy, extremely worrying is that caregivers have been waiting for years for a Law to be adopted, and it is only in 2019 that the National Draft Law 1461 “Measures to recognize and support the family caregiver” [30] was proposed to have the rights of caregivers recognized. Nonetheless, still at the end of 2021, the process for approval is at a standstill. The long-awaited draft law 1461 formulates a “first phase of regulation, aimed at the recognition and protection of the work done by the family caregiver”, recognizing them as a social and economic value for the country. Cittadinanzattiva and numerous associations of the National Coordination of Chronic Patients Associations (CnAMC) intervened on the draft law by sending specific comments to the XI Commission of the

Senate of the Italian Parliament. In the extensive document [31], reference is made to several aspects that should be improved in the draft law 1461. Among these, the organizations believe that the Caregiver Law should provide:

- "personalized" interventions modulated over time, based on the needs of the person and the caregiver and on the shared care path, that need to involve not only institutional resources but also "volunteering" and "community welfare";
- interventions that identify the caregiver as the owner of the life project with the consequent sharing of "informed choices" on the care path;
- training and orientation of the caregiver on rights, accessible services, operational and relational skills;
- simplification of the process of status recognition of the family caregiver;
- psychological support for orientation, also through support groups or self-mutual aid;
- coaching and assistance to caregivers by operators with specific and technical skills;
- support for the younger generation of caregivers, in particular to safeguard their right to study and social inclusion;
- recognition of care time in the workplace and tax incentives for companies;
- extension of contributions for the entire period of care and not limited to just three years;
- recognition of caregivers for the purpose of their inclusion in the category of arduous work.



**Figure 8:** Infographic realized by Cittadinanzattiva-Emilia Romagna's for the Report titled "What if caregivers did not really exist?", part of the civic campaign "I have the right to..."

### Motivating non-communicable disease patients at the European level: "This is Living" campaign

Equally significant as the need to recognize the support caregivers give to chronic patients is the need to motivate patients themselves. For this reason, at the European level, the "This is Living" communication campaign, developed by Boehringer Ingelheim Pharmaceuticals Inc., has been launched in the late 2021 to show its support on the pursuit of health and wellness in any shape or form, big or small, and to celebrate all the little things that we can do daily to improve our health. The campaign has involved in the production of materials and key messages Cittadinanzattiva, through its international branch Active Citizenship Network, together with the following patient organization representatives: European Coalition for People living with Obesity (EASO-ECPO) [32]; European Liver Patients' Association (ELPA) [33]; European Pulmonary Fibrosis Federation (EU-IPFF) [34]; Federation of European Scleroderma Associations (FESCA)

[35]; Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe) [36]; Lupus Europe [37]; Obesity UK [38]; World Heart Federation (WHF) [39].

The "This is Living" campaign offers a wide range of useful resources that can prove helpful for those living with a wide variety of chronic conditions, with specific sessions on kidney, liver, lung, or heart diseases, diabetes, obesity, autoimmune conditions, mental health conditions, and chronic conditions in general. In particular, Active Citizenship Network has contributed to the chronic conditions section with the drafting of two guides with the aim to help patients in preparing for the consultation with a health practitioner. The first guide called "Prepare to get the most out of your consultation" [40] helps patients to think about and gather all the information useful to get the most out of their health appointment, also taking into account that, of course, everyone has their own rhythms and routines to factor in. The second guide called "14 questions to ask your healthcare professional in your consultation" [41] aims at assisting patients to come

with questions in hand which can maximize the value of the appointment for both the patient and the healthcare team. A clear list will, of course, reduce the rush of the visit and ensure that important information isn't missed, but it can also strengthen the relationship with the healthcare provider. Getting a

full picture of the areas one is unsure of will no doubt help going forward. But sharing them also gives care providers a clearer understanding of the patient and of how his or her condition specifically impacts daily life.



**Figure 9:** Logos of the patient organizations part of the “This is Living” communication campaign, developed by Boehringer Ingelheim Pharmaceuticals Inc. and to which Active Citizenship Network is actively collaborating.



**Figure 10:** Communication material developed for the “This is Living” communication campaign, carried out by Boehringer Ingelheim Pharmaceuticals Inc. and to which Active Citizenship Network is actively collaborating.

## Conclusions

The Covid-19 pandemic has put us to the test and has enabled all of us to understand how health is a common good to be safeguarded. We have discovered ourselves fragile, isolated, but also with a renewed sense of responsibility, linked to the impact that our behavior may have on public health: a sense of responsibility that never abandons the caregiver in front of the needs of a patient suffering from non-communicable diseases. Today, let's not forget what we have experienced and look at the reality we live in with new eyes and a different mind. As life slowly gets back to something like normal, it can be difficult to pick up where we left off. Staying in control of our lives can be a daily struggle, especially due to the pandemic, and especially for those who live with a chronic condition. It's time for a change, to work together to take back control and to focus on our health again. On this regard, at the European level, high expectations are also linked to the full implementation of the European Pillar of Social Rights [42], a vital

instrument to achieve social justice and equality in the EU, proclaimed by the European Parliament, the Council and the Commission in 2017. The Pillar sets out 20 key principles [43] which represent the beacon guiding us towards a strong social Europe that is fair, inclusive and full of opportunity in the 21st century. Most of these, in fact, also apply to the situation faced by non-communicable disease patients and by their caregivers: life-long learning; gender equality; equal opportunities; active support to employment; **healthy, safe and well-adapted work environment; inclusion of people with disabilities; long-term care. To contribute to the dissemination of these principles among citizens**, in January 2020, Active Citizenship Network has been officially recognized by the European Commission's DG Employment, Social Affairs and Inclusion as an Ambassador of the European Pillar of Social Rights with the aim to support communication initiatives to spread the 20 principles of the Pillar and highlight the importance of a social European dimension.



**Figure 10:** Infographic on the 2017 European Pillar of Social Rights showing the three categories in which its principles are divided: equal opportunities and access to labour market, fair working conditions, social protection and inclusion.

## Declarations

Each of the authors confirms that this manuscript has not been previously published by another international peer-review journal and is not under consideration by any other journal. Additionally, all of the authors have approved the contents of this paper and have agreed to the submission policies of the journal.

## Authors' contribution

Each named author has substantially contributed to conducting the underlying research and drafting this manuscript. Additionally, to the best of our knowledge, the named authors have no conflict of interest, financial or otherwise.

## Conflict of interest

The authors listed on the first page declare that they do not have any conflict of interest.

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