



RESEARCH ARTICLE

The relevance of pain management & relief in the COVID-19 outbreak: an evaluation of the ten years implementation of the dedicated law in Italy

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Abstract

In 2010, Law no. 38 of March 15, 2010 on "Provisions for guaranteeing access to palliative care and pain therapy" (1) was issued in Italy. Law 38/2010 transposes and formalizes the provisions of the "Charter of rights on unnecessary pain" and in part of the "European Charter of Patients' Rights" promoted by Cittadinanzattiva and its international branch Active Citizenship Network, giving full legitimacy to the "Right to avoid unnecessary suffering and pain". A right for which many organizations of citizens and patients, together with numerous motivated professionals, fought hard, fighting the idea of pain and suffering as unavoidable components of the disease. Ten years after the publication of Law 38/2010, several steps have been taken and many progresses have been made, but there is still much work to be done for its full implementation. As a matter of fact, in Italy, Law 38/2010 is still little known by citizens and most of them ignore important rights for pain therapy and palliative care. This manuscript illustrates the main results of a civic survey promoted in 2020 by Cittadinanzattiva, which photographs how well-informed citizens are on the subject and how well they are able to assert their rights in Italy.

Keywords: Pain relief, Pain management: Civic survey, Covid-19, Italy

1 | INTRODUCTION

In 2010, Law no. 38 of March 15, 2010 on "Provisions for guaranteeing access to palliative care and pain therapy"[1] was issued in Italy. This is a highly innovative law, which for the first time guarantees access to palliative care and pain therapy by the patient, within the essential levels of care, in order to ensure respect for the dignity and autonomy of the human person, the need for health, equity in access to care, the quality of care and its

appropriateness to the specific needs.

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The Italian Law 38/2010 represents a model law on the subject worldwide; its contents are also the result of the commitment of civic organizations aimed at protecting the rights and dignity of people in the health sector. In particular, Law 38/2010 transposes and formalizes the provisions of the “Charter of rights on unnecessary pain” [2] and in part of the “European Charter of Patients’ Rights” [3] promoted by Cittadinanzattiva (the first Charter in Italy in 2005 and the second even first, in 2002, promoted at the European level thanks to its international branch Active Citizenship Network), giving full legitimacy to the “Right to avoid unnecessary suffering and pain”. A right for which many organizations of citizens and patients, together with numerous motivated professionals, fought hard, fighting the idea of pain and suffering as unavoidable components of the disease. Ten years after the publication of Law 38/2010, several steps have been taken and many progresses have been made, but there is still much work to be done for its full implementation. This manuscript illustrates the main results of a civic survey promoted in 2020 by Cittadinanzattiva [4], which photographs how well-informed citizens are on the subject and how well they are able to assert their rights in Italy.

2 | MATERIALS AND METHODS

The online and anonymous questionnaire to which 1028 citizens answered, between May and September 2020, was carried out by Cittadinanzattiva in collaboration with key national actors involved in pain management and in patients’ advocacy: Associazione AISD [5] - Associazione AISF [6] - Associazione AISLA [7] - Associazione AMICI Italia [8] - Associazione ANMAR Italia [9] - Associazione Antea [10] - Associazione APE [11] - Associazione CFS ME [12] – Palliative Care Federation Onlus [13] - Federdolore SICD [14] – FEDERFARMA [15] (1) – FIMMG [16] – FIMP [17] – FNOMCeO [18] – FNOPI [19] - ISAL Foundation Pain Research [20] - Maruzza Lefebvre D’Ovid Foundation [21] – LILT [22] – SIAARTI [23] - SIF [24] – SIMG [25] – SIOT [26] – SIP [27] - Italian Society of Palliative Care [28] – UILDM [29].

Well, 39% of the citizens who responded to the survey have a pathology that causes pain and more than 80% declare that it is chronic, i.e. continuous and/or recurrent pain that prevents them from carrying out their daily activities normally. Moreover, only 27% of these citizens received information about their rights in terms of pain therapy and unnecessary suffering.

Ten years after the passing of the law on pain enacted in 2010, Cittadinanzattiva showed how much citizens are informed about it through the data emerging thanks to a civic survey, presented on November 5th, 2020 during a web meeting, as part of the information campaign “We are not born to suffer” [30], carried out with the unconditional support of Pfizer.

The Final Report is available for the free download on the website of the association [31].

3 | RESULTS

Only 28% declare that they know the law 38 and the rights it provides. Here are in detail the areas and rights of which citizens seem to be better informed and those about which there is a lack of information that should be filled in order to make this law effective and enforceable.

How much citizens know about it:

Pain therapy

Just under three out of four citizens know that the law provides for the right to measure pain, regardless of the patient’s age and condition; just over half are aware that pain must be re-measured after treatment to assess whether it has had an effect; one out of three is aware of the appropriate instruments to detect pain.

Palliative care

Only 39% know that the law 38 also deals with palliative care and, of these, less than half are aware that such care is completely free and that it is aimed not only at those suffering from cancer but also other diseases such as dementia, Parkinson’s disease, ALS, chronic respiratory diseases.

Facilities for the "treatment" of pain

70% know that there are specialized centers for the treatment of pain; a little more (72%) know about hospices.

63% are aware that palliative care can be organized at the patient's home, in clinics, in hospitals, in facilities for the elderly (Residential Care Homes) and disabled (Health Residences for Disabled People) and mainly in hospices, as well as **51% know that to access palliative care you need a request from the general practitioner/pediatrician** of free choice or specialist doctor, after a joint evaluation between the health professionals involved and **47% know that you are entitled not only to health and pharmaceutical care but also to a psychological and social support** for the patient and his family.

One out of two states that there is a lack of information on these rights from the health professionals closest to the citizens, such as general practitioners and pediatricians of free choice.

Medications & painkillers

91% declare to be aware of the existence of specific medicines against pain but about 45% do not know that Law 38/2010 provides for the possibility for the doctor to prescribe on the NHS prescription (former red prescription) the medicines used in pain therapies (e.g.: opiate medicines), as is the case for any other type of medicine.

40% do not know that opiate medicines are safe and highly effective in most persistent painful diseases without making patients dependent or forcing them to use them over time.

4 | CONCLUSION

Since the publication of Law 38/2010 several steps have been taken, but there is still much work to be done for its full implementation. Despite the regulatory framework defined by law 38/10 and the subsequent provisions in the State-Regions Conference, as well as some judgments of the Constitutional Court and the Court of Cassation, the full enforceability

of the law is not yet ensured: as said, in practice, seven out of ten citizens do not know the law 38 of 2010 and the right that establishes to avoid the patient "unnecessary suffering".

In conclusion, in Italy, Law 38/2010 is still little known by citizens and most of them ignore important rights for pain therapy and palliative care.

The enforceability of this disregarded right becomes even more central in times of health emergency: we need palliative care and relief of chronic pain, even at a distance and with technologies and modalities compatible with the situation, but equally effective.

It is now known in Italy that to guarantee personal rights, the Law alone is not enough, and the tools to enforce "what is due" are not just the judicial ones. This is why Cittadinanzattiva proposes and promotes activities that favor and affirm rights in a constructive way: monitoring, evaluations, participation, informed information and empowerment of citizens, both at the National and at the EU level, thanks its EU branch called Active Citizenship Network.

In particular, in Italy, in order to overcome the current critical issues and take steps forward to effectively ensure the protection of the rights guaranteed by law 38, Cittadinanzattiva has launched an awareness campaign [32] aimed at all citizens with the purpose of making known and understanding fundamental rights when suffering from pain. At the same time, it calls on Institutions and relevant stakeholders, for the need to:

- standardize in the different territories-in terms of offer, but also in terms of characteristics and types - **local networks** for palliative care and models of care for patients with pain;
- integrate all the skills in the care process, including those always lacking in relation to the needs expressed by people and families (psychological and rehabilitative);
- make more homogeneous the training offer for health care professionals in palliative care, both in relation to university education and to the achievement of credits in Continuing Medical Education (CME);

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- increase the number of beds but also make active the peripheral network of pediatric palliative care and pain therapy, strongly lacking in almost all the national territory;
- periodically promote information campaigns on the law 38 addressed both to health care operators and professionals, starting from general practitioners, and to citizens.

At the EU level, Active Citizenship Network is carrying out the third edition of its EU project “EU Civic Prize on Chronic Pain - Collection of good practices” [33] with the aim to highlight existing good practices in several European countries in terms of struggle against pain. This third edition allows us to continuing expanding the “agora” of operators of good practices on pain, encouraging the exchange of experiences among health professionals, health-care providers, Institutions, civic associations, and patient advocacy groups. Exceptionally, for this edition, the Prize recognizes also outstanding initiatives that have been put in place, modified, or updated to face and mitigate the COVID – 19 pandemic consequences on chronic pain patients’ lives. About it, as Board member of the Pain Alliance Europe, Cittadinanzattiva is also supporting a PAE’s survey [34] on the consequences of the COVID-19 outbreak for people with chronic pain.



FIGURE 1:



FIGURE 2: The winners of the European Civic Prize on Chronic Pain, Second Edition (Award Ceremony within SIP Symposium, Brussels, 6 November, 2019). © Isabelle Pateer

5 | REFERENCES

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- [7] Associazione Italiana Sclerosi Laterale Amiotrofica
- [8] Associazione Nazionale per le Malattie Infiammatorie Croniche dell’Intestino
- [9] Associazione Nazionale Malati Reumatici
- [10] Associazione specializzata sulle cure palliative
- [11] Associazione Progetto Endometriosi
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- [22] Lega Italiana per la Lotta contro i Tumori

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[23] Società Italiana di Anestesia Analgesia Rianimazione e Terapia Intensiva

[24] Società Italiana Farmacologia

[25] Società Italiana di Medicina Generale e delle Cure Primarie

[26] Società Italiana di Ortopedia e Traumatologia

[27] Società Italiana di Pediatria

[28] Società Italiana di Cure Palliative (SICP)

[29] Unione Italiana Lotta alla Distrofia Muscolare

[30] “We were not born to suffer”, campaign on the access to palliative care and pain therapy

[31] “Non siamo nati per soffrire”, Nov. 2020

[32] To download the leaflet with the main information on the possibilities provided by the law, click here.

[33] European Civic Prize on Chronic Pain Collecting Good Practices - III edition 2020-2021

[34] PAE Survey on how Europe’s chronic pain patients are affected by the pandemic?

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