



Progetto IN-DOLORE 2014



Hospitals and the right to avoid unnecessary pain and suffering A civic survey

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Summary





- Brief introduction of Cittadinanzattiva and its commitment on pain therapy and to avoid unnecessary sufferances, in Italy and in Europe (ACN, Active Citizenship Network)
- Project «In-dolore 2014» promoted by Cittadinanzattiva, thanks to the unconditional support of Grünenthal:
- Methodology in pills
- > Restitution online
- Main results
- Political conclusions

OCTIVE CITIZENSHIP NETWORK CITTADINANZ OTTIVA

Cittadinanzattiva – a brief introduction

Cittadinanzattiva is a non-profit and consumer organization founded in Italy in 1978



It is independent from political parties, trade unions, private companies and public Institutions

Its main objectives are:

- the promotion of civic participation
- the protection of citizens' rights

Citizens: a fundamental resource for democracy opportunity to participate in everyday policy-making

It has +30 years experience in the protection of citizens' rights in the health sector:

Since 1980: Tribunal for Patients' Rights (TDM) - more than 200 local points and 10.000 volunteers



- 84 Citizen Advisory Centres (PIT) providing guidance, information and protection for free
- Since 1996: National Coalition of Associations for Patients suffering Chronic Diseases (CnAMC)



Active Citizenship Network – a brief introduction

Active Citizenship Network (ACN), created in 2001, is the European branch of Cittadinanzattiva

A flexible network of more than 100 EU civic and patient organizations

Member of:

- EU Health Policy Forum (EU Commission-DG Health and Food Safety)
- Active Citizenship Structured Dialogue Group (DG Home)



Our commitment at EU level:

- European Charter of Patients' Rights (2002)
 - 1. Right to preventive measures
 - 2. Right to access
 - 3. Right to information
 - 4. Right to consent
 - 5. Right to free choice
 - 6. Right to privacy and confidentiality
 - 7. Right to respect patients' time

- 8. Right to respect of quality standards
- 9. Right to safety
- 10. Right to innovation
- 11. Right to avoid suffering and unnecessary pain
- 12. Right to personalized treatment
- 13. Right to complain
- 14. Right to compensation
- **European Patients' Rights Day** (since 2007) celebrated every year on 18th April with local, national and EU events all over Europe





Active Citizenship Network – a brief introduction

- Civil Society Award (2007) of the European Economic and Social Committee for its work on citizens' rights
- MEPs Interest Group on "European Patients' Rights and Cross-border Healthcare" (2015)

The idea to encourage a MEPs Interest Group focused on patients' rights is linked to the widespread request of 100 civic and patient organizations sent to the EU Parliament to recognize officially the value of citizens' initiatives

Main aims of the Interest Group are:

- To actively support the celebrations of the European Patients' Rights Day and collaborate with civic and patient associations at national and European level
- To strengthen the protection of patients' rights in the European legislation, starting from the adoption of those included in the European Charter of Patients' Rights
- To promote initiatives that encourage and ensure among EU countries the respect of the European legislation focused on patients' safety and the protection of their rights. It could be done with the involvement of civic and patient associations, starting from the Directive 2011/24/EU on patients' rights in cross-border healthcare (is the first time that patients' rights is explicitly included in a EU legal context)





The engagement of Cittadinanzattiva in the Fight against Useless Pain

Over the last 15 years, Cittadinanzattiva has been increasing its contributions for the promotion and protection of citizens' rights **against useless pain** through the following strategic actions:

- **Protection** against violations of the right of individual citizens
- Collection and dissemination of best practices
- Promotion of information and awareness raising campaigns
- Actions designed to promote cultural changes
- Institutional mediation
- **Production of citizens' information** i.e. information *directly produced by citizens*, based on their point of view, starting from the data directly or indirectly acquired, to change the current state of affairs with a view to effectively improving the protection of citizens' rights and achieving conditions for effective protection, by means of follow-ups, enquiries and citizens' audits

The engagement of Cittadinanzattiva in the Fight against Unnecessary Pain

Let us abolish forced pain (2001) information campaign focused on particular population groups, e.g. the elderly people

<u>Charter of Rights against Unnecessary Pain</u> (2005) to declare and protect 8 fundamental rights often violated and obtain treatment in order to remedy



<u>We are not born to suffer</u> (2008) campaign. Creation of 40 local info points to facilitate dialogue between physicians and patients

<u>Against Useless Pain</u> a monitoring campaign on the state of implementation of the Charter of Rights against Useless Pain conducted in 33 Italian hospitals and health centres, by involving citizens and healthcare workers



The engagement of Cittadinanzattiva in the Fight against Useless Pain

<u>In-dolore</u> (painless) (2012) a campaign to dispel taboos and to offer advices, information and protection to citizens in order to do not suffer needlessly and also to provide information on the Italian state law n.38/2004 about pain registering on medical records and its treatment

<u>In-dolore</u> (2014) a monitoring project to check some aspects of the correct application of the law n.38/2010 in the hospitals, also by interviewing patients

2015: The member who will represent the citizens' associations in the Technical Committee of the Ministry of Health dedicated to the implementation of Law 38/2010 on palliative care and pain management is Tonino Aceti, national coordinator of the (TDM) Tribunal for Patients' Rights of Cittadinanzattiva

The engagement of Cittadinanzattiva in the Fight against Useless Pain

National Prizes on Pain

Over the years, Cittadinanzattiva has established specific national awards for the humanization of medical treatment and fight against pain:

- the "Andrea Alesini Award for the humanization of care" (since 1997) in which pain management is an important issue;
- the "National Prize on Chronic Pain Nottola Mario Luzi" (since 1997) organized by Cittadinanzattiva-Tuscany.

Goals of the Project In-dolore 2014



- Collect data to monitor the level of attention to the right to avoid pain and unnecessary suffering in hospitals
- Provide citizens with a concrete tool for knowledge, and at the same time make visible the attention to pain (Poster and website);
- Encourage the Committes «No Pain Hospital-Territory» to be a real agent for improvement.

Project promoted by Tribunal for Patients' Rights (**TDM**) – the Health Network of Cittadinanzattiva in Italy: more than 200 local points and 10.000 volunteers

To learn more on the Project:

www.cittadinanzattiva.it/in-dolore (in Italian)

Project In-dolore 2014



Steps for the improvement path advocated by the project:

- Voluntary subscription of Hospitals (they are all invited to join us!)
- Monitoring of hospitals and interviews to patients monitoraggio negli Ospedali e interviste ai pazienti
- Online Publication of results and work on-the-spot
- Press releases
- Measures of improvement shared and monitored with the Tribunal for Patients' Rights

Methodology in pills 1/2



Two tools for detecting data:



Checklist di 50 items in total



Short questionnaire to interview inpatients

Methodology in pills: the Checklist 2/2





50 items in total: > 7 areas dedicated to the Hospital in general

5 selected wards to focus on

1. Detection and treatment of pain	6
2. Corporate structure Ospedale-Territorio	9
3. Information to citizens	3
4. Staff Training	3
5. Access to medicines	4
6. Support and attention to individual needs	3
7. Pay attention to patients and commitment to improve	3
1. FOCUS PEDIATRICS	5
2. FOCUS OBSTETRICS AND GYNECOLOGY	3
3. FOCUS ORTHOPAEDICS SURGERY	4
4. FOCUS GENERAL MEDICINE OR INTERNAL MEDICINE	3
5. FOCUS EMERGENCY ROOMS	4
TOT items recorded	50



Progetto IN-DOLORE 2014





Per consultare i risultati del monitoraggio sul grado di attenzione al diritto ad evitare il dolore e le sofferenze non necessari, condotto negli Ospedali partecipanti, clicca sulle varie Regioni

19 hospitals in the North

The project involved:

46 Hospitals in 15 Regions (out of 21)

214 wards

711 inpatients

12 hospitals in the Centre

15 hospitals in the South and in the Islands

Leggi qui l'esperienza delle persone ricoverate

Data available online: transparency for citizens!



QUANTO È ATTENTO AL DOLORE QUESTO OSPEDALE



«How much this Hospital cares for pain»

Progetto IN-DOLORE 2014 ← Ospedale "CIRIÈ" (Cirié, To)

-Name and town of the **Hospital monitored**

Ha soddisfatto 31 elementi su 50 richiesti

Legenda

- Super-synthetic result: hospital 🕜 La struttura dichiara di soddisfare il requisito richiesto dalla domanda, avendo risposto "si"
- "La struttura dichiara di non soddisfare il requisito richiesto dalla domanda, avendo risposto achieved 31 items out 50
- La struttura dichiara che la domanda non è pertinente, quindi non è calcolata nel punteggio fina

SINTESI DEI RISULTATI: LE AREE DI INDAGINE

- Rilevazione e trattamento del dolore: 4 elementi soddisfatti su 6
- Sintetic results given by
- grafhic symbols Omma - Formazione / aggiornamento del personale: 1 elemento soddisfatto su 3
- for Areas
- and Focuses 🚳 🚱 🕝 - Sostegno e attenzione alla persona: 3 elementi soddisfatti su 3
- 🕜 🚰 👛 Ascolto dei cittadini e impegno per il miglioramento: 2 elementi soddisfatti su 3

SINTESI DEI RISULTATI: I FOCUS NEI REPARTI DI IND/GINE

PEDIATRIA: 4 elementi soddisfatti su 5

O O O - Informazione al cittadino: 2 elementi soddisfatti su 3

Main results: critical areas





Main results: critical wards (Focuses)





Main results: overview



- Patients' information on their rights as foreseen by Law 38/10 is very poor, and the same applies to patients' awareness about their rights.
- Healthcare providers often do not offer proper training to their staff.
- In 22% of the monitored hospitals only the entire staff (physicians and nurses)
 has received a specific training on pain treatment in elderly
- in 8 cases out of 10 there is a special space to fill dedicated to the pain treatment on medical records
- Almost all the patients (87.7%) were asked if they felt pain, but only in a case of two it was also measured the intensity with appropriate equipment
- The pain reported by patients was treated promptly but in most of cases with drugs
- Still a lot to do with pain treatment for children and elderly.
- Improvements in many wards, among which ERs

Some concerns 1/4





DETECTION OF PAIN

- A special section dedicated to pain treatment is provided on the medical record in 8 cases out of 10;
- Less frequent (just 63%) is the presence of specific sections to record pain intensity felt by people with speech difficulties (children, people affected by cognitive impairments)
- «No pain Hospital-Territory» committees, foreseen by L. 38/10 in Italia, are available in 70% of cases.

TRAINING OF PROFESSIONALS ON PAIN MANAGEMENT

Training of both doctors and nurses still needs to be fostered: only 4 health centres out of 10 have 75% of trained staff

Some concerns 1/4



INFORMATION TO CITIZENS

- Information on corporate websites is available in 7 cases out of 10, but it is not easily accessible;
- 60% of Hospitals do not provide informative materials on what they offer in relation to pain management

Patients' interviews show that:

- Only 24,9% of the inpatients interviewed were informed about their rights with regard to pain;
- 87.7% of them were asked if they felt pain;
- But only 45.2% of them had their pain intensity measured with appropriate equipment;
- In 16.4% of cases patients' affected by pain were not believed or their pain was minimized.

Alcune criticità 1/4





MATERNITY and GYNAECOLOGY

Just half of health providers adopts childbirth-analgesia, with a specific anesthetist available every day 24h:
This means that women can have epidural only if they are lucky.....

GENERAL or INTERNAL MEDICINE

Pain therapy addressed to elderly is a critical area: specific procedures are missing in 76% of general or internal medicine wards monitored.



Some concerns 2/4



ORTHOPAEDIC SURGERY

Use of tools to detect and measure pain is common practice.

BUT...

31% of the health providers do not offer postoperative procedures/techniques for pain management

Only 2 hospitals in 10 had trained 90% of their staff (doctors and nurses) on pain management

Some concerns 3/4



PEDIATRICS

69% health providers foresee that parents may assist their child before anesthesia and during a postsurgical awakening

But interviews to inpatients show that:

- 62.8% of operations with local anesthesia, at least one of the parents stood by their child before they go into the operating room;
- 59,5% of cases at least a parent was there during postoperative awakening of the child, which is a moment with a great psychological impact and pain

Alcune criticità 4/4



ACCESS TO MEDICINES

An area with decent results (71%), acknowledged by inpatients' interviews:

- 95.2% of cases patients' pain was treated in il dolore segnalato dal paziente è stato trattato
- 91.8% of respondents say pain care was «prompt»
- Pain was mainly treated with drugs (97.9%).

BUT..

Half of the hospitals periodically analyses on usage and pertinence of drugs adopted

ERSOnly 36% of health providers strutture è presente un protocollo di analgesia al triage che preveda che gli infermieri possano somministrare analgesici efficaci sul dolore moderato (quale ad es. paracetamolo)

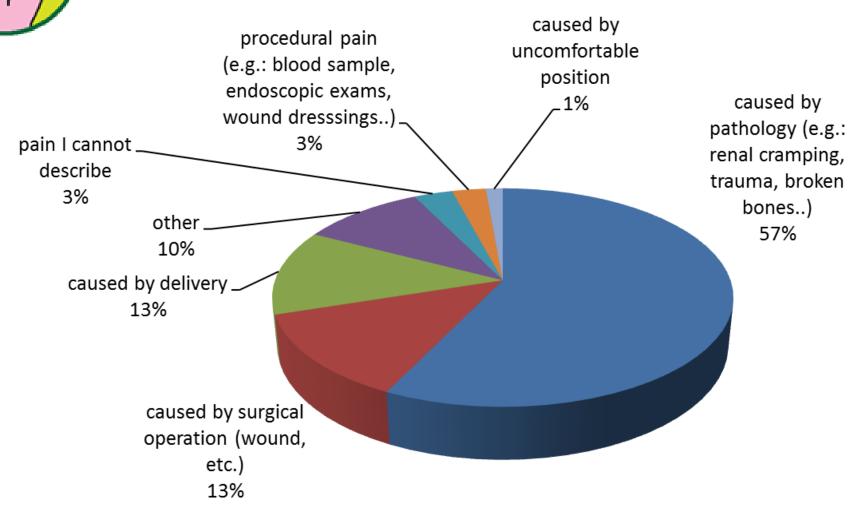
Solo nel 52% dei casi esistono protocolli o procedure per ridurre il dolore durante manovre o interventi dolorosi, come suture o rimozione di corpi estranei.



Inpatients'«voices»







Some political proposals



Local and national Institutions should work on:

- Activities to inform and raise awareness among citizens and health professionals
- protection of rights foreseen by the Italian Law 38/2010, by the EU Directive on cross-border healthcare and their implementation
- Increasing attention to elderly and children's needs to give the voice to those who do not have any
- Detection and treatment of pain through professional training, innovative solutions, new feasible management procedures
- taking care of patients' transitions from hospitals to their home, being the latter one of the biggest weaknesses of the health system





Pain is of course an indicator of quality for heathcare and "humanization"!

Can the civic point of view be useful?

We hope to have shown how organizations of citizens can give a contribution...

We believe in and work for cooperation in projects involving all the stakeholders: health institutions, group of citizens, patients, associations and pharma enterprises..





Thank you for the attention!

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