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A Civic Audit to Monitor Oncological Facilities across Italy: an Advocacy Tool in Line with the New Ambitious EU4Health Programme

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ABSTRACT

Across the world, oncological and chronic patients, including people affected by Noncommunicable Diseases (NCDs) have been left almost alone for a while now, and at the end of the emergency, we will count not only the deaths due to Covid-19, but also the number of people who died because they did not have a chance access the care that they needed. For instance, just talking about cancer, on the occasion of Cancer Patients' Day (May 17, 2020) some data were presented in Italy, showing how new cancer diagnoses have decreased by 52%, surgeries have been delayed in 64% of cases, and medical examinations in hospitals have decreased by 57%.

EU4Health is not only the EU's response to COVID-19, which has had a huge impact on medical and healthcare staff, patients, and health systems in Europe. The EU4Health programme will also focus mainly on urgent health priorities such as the fight against cancer, promoting its prevention and control across all EU Member States.

In Italy, the oncology field appears to be among those in which Cittadinanzattiva collects each year the highest number of reports and requests of support. In the past years, Cittadinanzattiva has promoted civic monitoring of oncological structures and facilities across the country, with the objective to detect, from the citizen's perspective, the strengths and weaknesses of these facilities and provide for an effective solution to improve their functioning. The experience described below points out the strengths and the weak areas that require improvement in oncological facilities and helps the citizen learn about the available services with the purpose of choosing where to seek care for him/herself.

Keywords: EU4Health; Cittadinanzattiva

INTRODUCTION

According to the European Union's (EU) reports on health, cancer is recognized as one of the major contributors to premature deaths in the EU. It has an impact not only on individual health, but also on the national health and social systems, the governmental budgets and the productivity and growth of the economy, including a healthy workforce. Evidence suggests that there is an urgent need for the development of more effective and accessible health systems in order to ensure that all EU citizens have access to effective cancer prevention and care. The European Commission has many times highlighted the need to create a European plan to fight cancer and to support Member States in improving cancer control and care as a way to reduce the suffering caused by this terrible disease. Recently, a number of initiatives have been established to fight cancer in the EU, starting from the "Europe's beating cancer plan" [1] and the new ambitious EU4Health programme for 2021-2027 [2]. The pandemic has had a huge impact on medical and healthcare staff, patients, and health systems in Europe. EU4Health will provide funding to EU countries, health organizations and NGOs with the aim to: boost EU's preparedness for major cross border health threats by creating reserves of medical supplies and healthcare staff and experts for crises; strengthen health systems so that they can face epidemics as well as long-term challenges by stimulating disease prevention and health promotion in an ageing population, digital transformation of health systems, and access to health care for vulnerable groups; make medicines and medical devices available and affordable, advocate the prudent and efficient use of antimicrobials as well as promote medical and pharmaceutical innovation and greener manufacturing. The EU4Health's focus has been mainly on urgent health priorities such as the fight against cancer, promoting its prevention and control across all EU Member States and promoting international cooperation on other non-communicable diseases.

In Italy, there has been a steady increase in the number of patients with a history of cancer in recent decades: there were less than

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1.5 million in the early 1990s, 2.2 million in 2006, and about 3.3 million in 2018 [3]. The oncology field appears to be among those in which Cittadinanzattiva collects each year the highest number of reports and requests of support.

Cittadinanzattiva is an NGO [4], founded in Italy in 1978, which promotes citizens' activism for the protection of rights, the care of common goods, and the support for people in conditions of weakness. Since 2001, Cittadinanzattiva is active also at the EU level through its international branch Active Citizenship Network, officially recognized as a relevant stakeholder by the EU Institutions [5].

Starting from the data collected about the unmet need of citizens and patients, in the past years Cittadinanzattiva has promoted a civic monitoring of oncological structures and facilities in Italy with the objective to detect, from the citizen's perspective, the strengths and weaknesses of these facilities and provide for an effective solution to improve their functioning. The experience described below, in light of the impact of the Covid-19 pandemic, appears to be extremely relevant despite some years have passed since it was first realized.

Civic monitoring of oncological facilities: overview of the results obtained

The civic monitoring on oncological facilities was carried out by Cittadinanzattiva – Tribunal for Patients' Rights thanks to the unconditioned contribution of MSD Italia. At the collection of all data CIPOMO [6], which stands for "Collegio Italiano dei Primari Oncologi Medici Ospedalieri (Italian Association of Consultants in Medical Hospital Oncology), has actively collaborated. The involved associations were several, AIL (Italian Association against Leukemia) [7]-Lymphoma and myeloma ONLUS-FAIS ONLUS (Federation of Incontinent and Stomata Associations) [8]–WALCE (Women Against Lung Cancer in Europe) [9]–FNOPI (National Federation of Nurses Colleges) [10]-Istituto Nazionale dei Tumori di Milano (National Cancer Institute of Milan) [11]- Ospedale Civile di Ovada (Civil Hospital of Ovada) [12]–SIFO (Italian Hospital Pharmacy Society) [13]-S.I.P.O. (Italian Psycho-oncology Society) [14].

From the monitoring, a positive opinion on the customization of patient's health care emerged. However, the management of waiting times, computerization and continuity of care should be improved. Most health care structures guarantee a proper care of oncological patients through specialized teams, a careful attention to the customization of the treatment course and the release of the exemption code already in case of clinical suspicion in the 50% of the facilities. The communication with the patient and his/her family, as well as the appropriateness and the comfort of spaces in hospital wards and day hospitals, is also well organized. Nevertheless, several critical aspects still exist. First of all, the access to diagnostic services is not guaranteed within 72 hours from one facility out of four. Furthermore, there are many delays regarding the access to hospital medicines and a lack of staff recruitment in response to the institution of oncological networks. Another sore point is also the assessment of the continuity of care with unsatisfying percentages for the absence of the case manager figure in half of the facilities and the lack of coordination with general practitioners during the discharge of the patient. Some progress should be made also concerning the evaluation of the consumer's satisfaction, along with transport services between household and hospital to accommodate the cultural, ethnic, and religious differences. Another area that quickly requires improvement, considering we live today in a completely digitalized world, is the one regarding the computerization of procedures, starting by the electronic health file available only in half of the cases

RESULTS

62 oncological facilities of 18 different Italian regions have been monitored for the civic survey (the facilities of Basilicata, Friuli Venezia Giulia, and the autonomous region of Bolzano did not join). In 23 facilities, the Oncological Day Hospital (ODH) was monitored, while in 39 of them both the ODH and the oncological hospital wards were monitored. The monitoring questionnaire examined 112 factors, with the objective to investigate: the respect of the 14 rights of the European Charter of Patients' Rights [15], the attention of the facilities to the needs and rights of the person with cancer and of his/her family, the capacity of care, the provided services, the level and the quality of the assistance to the patient, and the availability of oncological medicines. Here are in detail all the results that emerged from the civic monitoring.

Organizational aspects

When the civic monitoring was realized [16], oncological networks, intended as "the coordination of all the actions that concern the assistance of the cancer patient, both inside and outside the hospital", were active only in few regions: Veneto, Piemonte, Lombardia, Toscana, Trentino, and Umbria, and were about to be activated in Emilia Romagna, Friuli Venezia Giulia, Lazio, Liguria, Alto Adige, and Sicilia, while in all the other regions they were not yet activated. From the investigation, it results that 52% of the monitored facilities belong to a formal oncological network, while all the others consist mainly of facilities that work online to guarantee the necessary services despite the fact that they are not involved in any formal regional oncological networks.

All facilities are equipped with an oncological Day Hospital, with the radiotherapy service active in 55% of the facilities, the emergency room or Accident and Emergency Department (A&E) in 81% of them, the Center for Pain Therapy in 89%, the service of Psycho-oncology in 73% of them. Less widespread are the services for oncological rehabilitation (present in 43% of the facilities), and the hospice (in 44%).

In 98% of the cases, the patient can contact the CUP (the Italian information desk to book health appointments) [17] that, in 75% of the facilities, guarantees the centralization of appointments for the entire treatment process, and, in 85% of the cases, it guarantees higher opening hours of the facilities in contrast to the average 36 weekly hours. he possibility to make an appointment online is only guaranteed in 28% of the facilities.

Despite 70% of the facilities is equipped with a management software for organizing and managing health care processes, these systems are still not entirely satisfactory. For instance, they do not communicate with the screening centers and do not allow the evaluation of the PDTA's effectiveness [18]. In addition to this, the electronic health file is used in the daily practice only in 55% of the facilities and only in 41% of them it is shared with the family doctor.

In more than 90% of the facilities, a reception service exists in order to inform the citizen on the services and appointments and for patients to book the next follow ups to the visits.

The citizen's path in the service

One facility out of four does not guarantee the access to screenings within 72 hours to patients with a suspect cancer diagnosis. On

the other hand, the access times to the possible surgical procedure are guaranteed almost in nine out of ten facilities (87%), within 60 days from the screening. The same percentage (89%) guarantees the start of the chemo or radio-therapeutic treatment. However, only 71% of the facilities provides for the monitoring of waiting lists and the sending of all data to the regions. A good aspect concerns 50% of the facilities which assigns the cancer pathology exemption code 048 already from the clinical suspicion.

95% of them declares to guarantee the specialists' involvement in the diagnosis and care process but, in listing the figures of the multidisciplinary group, it is discovered that some remain absent: this is the case of the social worker (absent on four teams out of five), of the pharmacist (absent in 69% of the cases), of the pain therapist or specialist in palliative care (absent in half of the cases), of the psychologist (absent on one case out of three) and of the nurse (absent on one case out of four). Moreover, only 20% of the facilities involve in the group the general practitioner. The case manager, that is a sort of tutor for the patient, is present in one out of two.

In 42% of the structures maximum 15 days on average are needed for the insertion of new medicines in the drug formulary, while the introduction of life-saving medicines takes from 3 to 4 months (7%) and from 4 to 6 months (9%). In addition to this, only 52% of them provide for procedures to support the cost of medicines that did not pass from National Health Service.

Another area that should be improved is the one regarding the management of the stocks and supplies of antineoplastic medicines since only 51% of the facilities possess a software capable of posting online this information together with the other facilities.

Concerning the clinical trials, despite 81% of the facilities performing research, only 53% of them are part of a network in which information on ongoing trials are shared, only in 35% a procedure for the sending of the patient to structures with active trials is provided and only in 30% of them all the information on the trials is published on websites.

A huge positive side is the efficiency of the customization of the cures, guaranteed in 97% of the structures, and the thoroughness on the attention to pain, guaranteed in 94% of them

Citizen orientation and humanization

Almost all the facilities dedicate a contact person of the team to the communication of the cancer diagnosis, which takes place through direct and personal interviews with the patient. 95% of them offer free psychological support for patients who request it and 77% of them provide it in a structured and continuous way. Several critical areas remain. Today, 66% of the facilities still do not offer guesthouse services for the families of hospitalized patients. Furthermore, the transport from home to the facility and vice versa, for chemo and radiotherapy, is guaranteed only in 60% of them and the administrative bodies assigned to handle bureaucratic practices are guaranteed only in 23% of the facilities. In the context of cultural, ethnic, and religious non-discrimination, only 48% of the facilities offer a cultural mediation service, 53% an interpreting service and only 19% offer multilingual informed consent forms. Another negative data is that regarding the absence of a dietary handbook that respects religious beliefs, present only in 55% of the structures.

From a comfort point of view, 77% of oncology wards have rooms with no more than two beds, toilets inside the rooms (92%) and in 54% of them air conditioning systems adjustable by patients. Only 33% of the wards make the Wi Fi network available. The lounges reserved for hospitalized patients to meet relatives and friends outside the ward were also monitored. These lounges were mostly comfortable, providing for a suitable number of seats (for 87% of the structures), air conditioning systems (79%), the presence of television (in 74%), drink dispensers (in the 64%), library (in 54%). Breakfast is served in 92% of the departments after 7:00 am, lunch in 95% after 12:00 pm, dinner after 7:00 pm in 62% of the facilities. 90% of the departments offer the choice to patients, who do not have restrictive diets, between two or more menus.

In Day Hospitals (DH), TV can be found in 90% of the cases, libraries and cable radio systems in 47% of the cases, chairs with MP3 headphones in 21% of them. 79% of DH offer mid-morning drinks and snacks. As for parking, 92% of the structures have one reserved for patients and visitors. 81% have free parking spaces while 47% have parking fees. However, environments where architectural barriers are still present still exist, for instance, only 90% of the structures are totally accessible in the Day Hospital.

Participation and transparency

The data indicates grey areas. 61% of the facilities constantly perform investigations on the satisfaction of the clients, only 65% makes annual audit on the evaluation of the quality and of the performances and, among the indicators made for the purpose of performance evaluations, only 71% of them provides for the monitoring of the waiting times and for the sending of all data to regions [19].

CONCLUSION

Overall, oncological facilities present many strengths and are mostly well structured and well organized. However, access to diagnostic services in a timely manner, staff recruitment, coordination with general practitioners and other health figures, transport services, and the computerization of procedures are essential aspects that many times hinder a good functioning of the structures. Cancer patients' lives can be facilitated by simply guaranteeing, in all facilities, free access to medical examinations, which can be obtained through the recognition of the cancer pathology exemption code 048 mentioned above already during the clinical suspicion. The fund for the innovative medicines foreseen in the Italian budget law should be used to reduce both access time and the inhomogeneity for the innovative oncological medicines in hospital facilities. Strengthening the commitment to better qualify the health care path and the relation between hospital and territory, to avoid that the person in the transitional phase between diagnosis and treatment feels aggravated by further unnecessary burdens, is also necessary. Finally, the evaluation activity of services' quality needs to be strengthened, making all the results transparent and accessible.

Not being able to correctly address the inadequacies highlighted above, which have long been known to both institutions and professionals, has meant that the impact of the Covid-19 pandemic, with the suspension of cancer screenings and the difficulty of ensuring continuity of care for patients, including cancer patients, has put at serious risk 20 years of progress in cancer care in Italy.

Also for this reason, in the first part of 2020, in full pandemic, together with representatives of medical-scientific communities such as Periplo - which represents the Italian cancer networks - and the Foundation for personalized medicine, Cittadinanzattiva has

sent to the National and Regional Health Authorities, a request in order to adopt new measures to guarantee the continuity of treatment for cancer patients outside hospitals, in a safer context, able also to decongest the hospitals, and to adopt a strategic investment on territorial healthcare that has been abandoned for too much time.

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