

RCE-ESMO-ESO

Training Course for Rare Cancer Patient Advocates 2022

Cancer care: ensuring that digitalisation benefits rare cancer patients <u>The physician's perspective</u>



European Reference Network

for rare or low prevalence complex diseases

Network Adult Cancers (ERN EURACAN)

Member

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ISTITUTI DI RICOVERO E CURA A CARATTERE SCIENTIFICO

Italy and COVID-19 pandemic Istituti Fisioterapici Ospitalieri (IFO-Rome) experience



After the WHO declared the novel coronavirus (SARS-CoV-2) outbreak a global health emergency, Italy declared a national lockdown on 9th March 2020.

In April 2020, many hospitals were reorganized in Hub and Spoke Units to ensure the implementation of intensive care beds and new multidisciplinary networks with infectious, medical, pulmonology and resuscitation specialties.

 SECURITY MEASURES TO REDUCE CONTAGION (avoid gatherings, triage, use of personal protective equipment), EARLY IDENTIFICATION, ISOLATION AND REFERRAL OF SELECTED CASES IN COVID-19 STRUCTURE WERE MANDATORY.

Istituti Fisioterapici Ospitalieri (IFO) in Rome was identified as the referral centre for "non COVID-19" oncological diseases for the Lazio region. The reorganization of clinical activities and the implementation of communication tools with oncological patients became a priority.



Italy and COVID-19 pandemic Istituti Fisioterapici Ospitalieri (IFO-Rome) experience



• After the <u>first emergency phase in which "unprotected"</u> communication tools (such as phone, fax or e-mail) were used to ensure continuity of care, the implementation of social distancing strategies passed through the promotion of <u>DIGITALISED</u> <u>INTERACTIONS</u>.

 The IFO project for the use of telemedicine started in 2020 on the occasion of the pandemic state of emergency, through a platform called DNMLAB (already in use for the application of a Narrative Medicine project).





TELEMEDICINE (DBMLAB platform)

Objectives

- During the emergency phase
 - a) provide <u>remote assistance</u> to cancer patients;
 - b) satisfy the need for assistance while avoiding <u>unnecessary patient access</u> to the facility;
 - c) optimize the times and methods of remote contact, in compliance with privacy regulations.

Past the emergency phase

a) optimize the <u>organizational methods of the care model</u>, thus promoting the efficiency of the entire system; (i.e. management of resources and time; multidisciplinary integration of the structures)

b) detect and evaluate the need, directly expressed by the patient/user, and guarantee its satisfaction

c) measure the effects of the introduction of the methodology in clinical practice





TELEMEDICINE (DBMLAB platform)

Target population

a) patients already in care at the IFO;

b) patients (or patients' caregivers) that have an ongoing cancer problem and who need a first consultation (LIMITED TO THE EMERGENCY PHASE);

c) health professionals who want a specialist consultation for their patients.



Tool

DNMLAB platform which, in the part dedicated to telemedicine, presents:

- a) a patient card for the collection of anamnestic data;
- b) a section for uploading reports, images and documents for the exchange between

patients and physician (or between physicians) in a protected environment;

- c) a communication page to exchange messages with the referring IFO physicians;
- d) the possibility to video call (activated exclusively by the referring IFO physician);
- e) a calendar for appointments.

Mandatory:

- registration of all healthcare professionals involved;

- digital consent signature (patients and/or caregivers) to use the tool and to take note of the data processing policies in accordance with current legislation.









TELEMEDICINE (DBMLAB platform)

Operational phases

<u>PHASE 1</u>: construction of "**digital specialist clinics**", i.e. <u>customized online</u> <u>environments for each unit;</u>

<u>PHASE 2</u>: implementation of the use of the platform by **promoting multidisciplinary** interaction/integration between the practitioners of the various "digital clinics"; activation of a teleconsultation area on the institutional website, dedicated to professionals.

<u>PHASE 3</u>: creation of multidisciplinary environments and paths, thanks to the integration of pre-existing digital environments and the construction of new "transversal clinics".

<u>PHASE 4</u>: Design and conduction of clinical research projects aimed at validating the introduction of telemedicine in the clinical and managerial practice of a national cancer institute.







Istituti Fisioterapici Ospitalieri (IFO)-Rome

IRCCS Regina Elena National Cancer Institute (IRE) IRCCS San Gallicano Dermatological Institute (ISG)

EMERGENCY PHASE

OncOnline Regina Elena

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servizio di telemedicina

Ci prendiamo cura di te

ACCED

Telemedicine Services
OnconLine e DermOnline

DermOnline San Gallicano

servizio di telemedicina

Ci prendiamo cura di te







Main reasons for the non-use of telemedicine (25% or more of respondents)

- Need to evaluate the patient in-person for the assessment of parameters related to the physical examination (e.g. postoperative control);
- Need to use instrumental equipment (e.g. radiology)



Telemedicine Istituti Fisioterapici Ospitalieri (IFO-Rome) experience Physicians' user survey results



Main reasons for the non-use of videocalling (25% or more of respondents)

The video call does not necessarily add useful information during remote consultation, considering the possibility to exchange contents and documents within the platform.

Preference of other and more immediate communication channels (messages, emails or phone calls) that have become familiar, often also for patients.

 Technical and organizational problems (lack of a sufficient number of equipped workstations, organization in relation to shifts, connection problems)



Telemedicine Istituti Fisioterapici Ospitalieri (IFO-Rome) experience Physicians' user survey results



Indications for the use of telemedicine in cancer patients beyond the pandemic emergency in order of preference:

- sending of documentation (reports, prescriptions, etc.) to conclude the clinical picture after a recent visit;
- occasional follow-up visit of a patient from outside the region or unable to access the hospital
- monitoring of patients in home therapy (e.g. dose adjustment, adverse effects, etc.)

• other:

- Patient management during oral chemotherapy
- Telerehabilitation, telemonitoring and neurological telesupport
- Telepsychotherapy when the patient prefers a remote interview
- Consultations between internal specialists (e.g. Disease Management Team) or external ones (e.g. attending physician)
- Teleservice nursing (e.g. ostomy management, teleassisted medication)
- Evaluation and adaptation of the nutritional plan
- -Preliminary evaluation of rare diseases for further in-person pathway indications
- control of the clinical picture (e.g. toxicity, postoperative course, etc.)
- renewal of the treatment plan in chronic therapies



Telemedicine Italian legislation



 Telemedicine is acknowledged in Italian legislation and was strongly recommended during the COVID-19 emergency as a <u>recognized</u> <u>communication tool with the purpose of protecting privacy</u>.

- Apart from research projects, since 2020 the Italian National Health System has taken steps to develop telemedicine services, making them an integral part of the daily activities of clinical assistance. Under development:
 - definition of common platforms,
 - integration of telemedicine within work shifts,
 - methods of reimbursement of the procedure
 - traceable booking methods







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Rare Tumors Rare alone.....but not together about 25% of all newly diagnosed tumors

- Frequent therapeutic inappropriateness
- "Orphan" diseases from many points of view
- Expertises on <u>all</u> rare tumors non always present in the same hospital (even including research institutes and academic facilities)

• Frequent geographical distance between the patient's residence and the reference centre for the specific rare tumor.



Limits

- Absence of minimum requirements (adequate digital literacy of the patient/care giver; necessary devices and network connection) to use the tool.
- Possible limitations of video calling with regard to an accurate assessment of clinical conditions.
- Emotional "distance" between doctor and patient when communicating bad news in tumors often orphan of valid therapeutic options (like rare tumors!).





Opportunities

Patients already in the hospital's charge

- Follow-up of known patients who do not need urgent evaluation (neither symptoms nor clinical/radiological signs of disease progression for which a face-to-face approach is necessarily maintained)
- Monitoring of chronic therapies (surveillance of adverse events that do not require hospital access) and of oral oncological drugs with possibility of drug domiciliation.
- Multidisciplinary sharing of known clinical cases (teleconsultation and telecollaboration between specialists and general practitioners, when necessary)
- Simultaneous care activities in case of frail patients still in active oncological treatment.





Challenges (1)

- "Virtual" referral of patients with rare tumors to reference centers with specific expertise (often distant from the patient's residence) for:
 - → second opinion for patients with rare tumors already being treated in non-referral centers
 - \rightarrow evaluation for inclusion in clinical trials
 - → evaluation for genomic profiling and discussion in the context of molecular tumour boards
- Histopathological review (telepathology)
- Tele-consultation and tele-collaboration activities between external specialists or other attending physicians who follow the patient and "expert" specialists to remotely share the optimal therapeutic strategy.





Challenges (2)

- Tele-consultation and tele-training activities to support GPs in early recognition and early referral of <u>new</u> patients with rare tumors to regional/national reference centers.
- Telematic awareness campaigns on rare tumors in schools and universities (neoplasms of adolescence/young adults) and in the workplaces.
- Implementation of information and training initiatives on rare tumors through telehealth tools to increase patient empowerment.





Thank you!