

SWALLOWAPP: IMPLEMENTATION OF THE QUALITY OF CARE AND FOLLOW-UP FOR THE ONCOLOGICAL DYSPHAGIA PATIENT

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ABSTRACT

The COVID-19 pandemic has dramatically altered the provision of routine medical services and has imposed unprecedented challenges on the healthcare system. This contingency inevitably also had repercussions on the management of patients with dysphagia resulting from head and neck tumors. Technology has provided many useful tools to stem this discomfort and among them, the creation of an app seemed to us an advantageous way to go. The theoretical conceptualization underlying the birth of this project is represented, on the first step, by the observation that mobile apps for smartphones provide an ideal platform for providing educational support to patients; second step, the patients need to have these informations. A need that has certainly increased during the health emergency, as patients were unable to have easy access to the hospitals where they were followed up during the follow-up. It is important to emphasize that this tool is not a substitute for the direct relationship with the speech therapist, nor is it presented to patients as an alternative to it; however, it can be considered as a constant and continuous support to the patient and his family, as it represents one of the useful tools to best combine the existing professionalism and the needs of patients with swallowing disorders and those who care for them, exploiting the progress of technology. We tried to quantify the benefit received by the patient to assess how much SwallowAPP (the name we gave to the aforementioned App) can impact on the perception of care received at a time unfavorable to face-to-face relationships. In the same way, we evaluated the ease of use of the system, a fundamental requirement for its acceptance by the user. From the careful analysis of the work carried out, SwallowAPP has shown that implementing the quality of care provided to the swallowing disorders during the early stages of subsequent follow-up to surgery, it had a strong impact especially on the patient's quality of life.

INTRODUCTION

Telemedicine during a health emergency

On 11 March 2020, the World Health Organization (WHO) declared the 2019 coronavirus (COVID-19) outbreak as a pandemic. The confinement of the population and the impact of the epidemic on health systems have disrupted routine care for non-COVID-19 patients [Ohannessian et al, 2020] causing a global public health emergency [Humaid et al, 2020]. In this context, telemedicine has been promoted and expanded to reduce the risk of transmission, especially in the United Kingdom [Greenhalgh et al, 2020] and in the United States of America [Hollander et al, 2020]. Telematic health services have been reported in China [Liu S. et al, 2020] and also in Australia [Zhou X et al, 2020]. The technological improvements and cost reduction of telemedicine solutions, combined with both high-speed Internet and the mass diffusion of smartphones, make their implementation possible [Ohannessian et al, 2020]. Indeed the telemedicine was seen as a major innovation during COVID-19 pandemic [Doarn CR et al, 2020; Gill S et al, 2020]. On March 13, 2020, with the emergency act declared in the United States, telemedicine was officially authorized and reimbursed [Doarn CR et al, 2020]. Italy has quickly become the second most affected country in the world by the coronavirus

pandemic, reports Marta Paterlini on the front lines of a country in total blockade, which does not include telemedicine in the essential levels of assistance granted to all citizens within the National Health Service. All is changed on March 24, 2020, when in this date has been published an important document on telemedicine and for the proposed technology of monitoring systems by the Ministry for 'technological innovation and digitization, by the Ministry of Health, the National Institute of Health and by the WHO [Innova for Italy, 2020].

Telemedicine and dysphagia in patients with head and neck cancer

The global pandemic of the new COVID-19 disease has dramatically changed the provision of routine medical services and has imposed unprecedented challenges on the healthcare system. This influenced patients with swallowing disorders after head and neck tumors. Dysphagia is the term used to describe swallowing disorders. It represents one of the most common complaints for patients with head and neck cancer, before, during and after treatment. Any head and neck tumor in fact, it can cause swallowing disorders through various mechanisms, as: the pain caused, the motor limitations caused by the infiltration of the nervous structures, the sequelae of surgical exeresis, the type of reconstruction intervention, the effects collateral to radiotherapy and /

or chemotherapy. Patients undergoing demolition surgery involving the oral, pharyngeal and / or laryngeal district will develop, in the post-operative period, alterations in the swallowing function, which result in intra-swallowing and / or post-swallowing dysphagia. The presence of tracheal cannula and the concomitance of any radiation or chemotherapy treatments complicate the management of these patients, who often require multidisciplinary care from speech therapists and otolaryngologists in clinics dedicated to swallowing disorders. A detailed inventory of symptoms, oral-motor examination, clinical evaluation of swallowing, objective studies on instrumental swallowing, intervention on swallowing and monitoring of progress are still essential for these patients during the COVID-19 pandemic. So, knowing the significant risks associated with delayed care for patients with swallowing difficulties, the importance of timely assessment and management of dysphagia should not be underestimated [Fritz A et al., 2020]. Similarly, awareness must grow that mortality from COVID-19 is higher in patients with chronic diseases, immunosuppressive conditions and older age [Xia Y. et al, 2020; Sorbello M. et al, 2020]. It is therefore obvious that cancer patients are at a higher risk of COVID-19 complications [Zhang L. et al, 2020] as neoplasm and anticancer therapy cause an immunosuppressive state [Liang et al, 2020]. In this regard, a safe and reasonable course of treatment for dysphagia can still be implemented with changes in the configuration and application of new technologies. So, the use of telemedicine defined as the provision of health care offered remotely with any telecommunication tool, such as secure telephone, video conferencing, email, messages and applications for mobile devices, with or without video connection, when appropriate, is recommended. [Wosik et al, 2020; Negrini et al, 2020]. A study by F Yildiz and B Okuzoglu in Turkey showed that telemedicine could open a new era for oncology specialists, suggesting that further application of this method after the COVID19 pandemic should be seriously discussed as consists of an efficient resource for the care of patients with needs in the speech therapy and otolaryngology field, allowing for remote care. Treatment of head and neck cancer consists of a rigorous regimen of combination therapies that produce a multitude of painful symptoms and side effects. Although it is almost impossible to circumvent the physical insults and psychosocial relapses caused by such treatment, some interventions aimed at educating and supporting patients during treatment have been successful. Tele-practice models can identify the concerns and needs reported by head and neck cancer patients and caregivers in order to manage them consequently [Wall LR et al., 2015]. Since dysphagia increases the risk of malnutrition, dehydration, weight loss and aspiration pneumonia [Wirth R. et al., 2016], it is imperative to detect symptoms of dysphagia early and provide adequate preventive support to reduce morbidity and improve health-related quality of life

[HyangHee Kim et al., 2020]. In this regard, the mHealth apps can offer an objective approach to patient adherence documentation, and can also fill any existing or planned gaps in access to swallowing therapy or in receiving educational information. These are the results achieved by a qualitative study on the use of mHealth apps as adjuvants for home rehabilitation after treatment for head and neck cancer [Constantinescu et al., 2017]. Years earlier, a research group based in the Netherlands developed and tested a comprehensive electronic health information system using a simple telemessage device in head and neck cancer care [van den Brink JL et al., 2005]. The same type of electronic media has been successfully designed by van de Brink JL et al. : consists of a system provided to patients with head and neck cancer during the first six weeks after discharge, using the device, patients can having access to information, contacting other patients through a forum and communicating by sending messages, they can also be monitored at home through electronic questionnaires [Van de Brink JL et al., 2005]. The multiple benefits of interactive health technologies support the potential of tele-practice to reduce the care burden of the patient with head and neck cancer and improve the provision of services for these patients [Murray E. et al., 2005]. A multidisciplinary cancer research team from the head and neck district of Louisville, Kentucky, led by the hypothesis that a telemedicine intervention can educate and empower patients, facilitate communication with their healthcare professionals, and improve symptom management during the treatment, it has developed algorithms for the management of frequent symptoms after the treatment of head and neck cancer, to be communicated through a simple telematic messaging device: "Health Buddy", which offers daily support and information based on the needs of the individual patient , it has proved to be a useful complement to traditional treatments when the treatment regimen is complicated and fraught with distressing symptoms; it also prevents the patient from being overwhelmed by the amount of information provided at the start of treatment [Head A. et al., 2009]. An asynchronous tele-practice system has recently been reported to improve adherence to speech therapy for swallowing during chemo-radiotherapy treatment [Wall LR et al., 2017]. The "SwallowIT" service uses instructions and interactive supports (video, images and text) and allows therapists to remotely monitor the therapy; its feasibility has been demonstrated, taking into account the perceptions of users, in terms of flexibility, support and motivation. The difficulty of these patients in adhering to the recommendations for treatment, it has motivated the birth of several customized mobile applications, such as "VibrentTM", a software to be used in addition to routine clinical visits and instructions given by the speech therapist, which has proven its effectiveness in improve patient adherence [Starmer et al., 2017]. Particularly after radiotherapy or chemotherapy (C / RT) for head and neck cancer, patients regularly

return to the hospital for outpatient reviews with speech therapists and nutritionists for acute symptom monitoring, nutritional management, and rehabilitation of swallowing and communication. A home telematic care model (TMOC) was compared with a standard care model (SMOC) dedicated to these patients. The home service delivery model reported high satisfaction, the benefits included the convenience and comfort of accessing care from home, so as to avoid the burden of fatigue, time and associated costs for different hospital appointments [Collins A. et al., 2017]. Regarding the readiness of the head and neck cancer population to adopt telepractice models, two first surveys conducted in 2005 found low rates of computer use and a preference for receiving health-related information in a traditional way [Lea J. Et al., 2005; Kagan SH et al., 2005]. However, recent data show a marked change in the results. Cartmill et al. in 2016 reported a high level of computer literacy in patients with oropharyngeal cancer. 91% of patients reported daily use, demonstrating "confidence" in the progress of technology and a predisposition in its use for health-related activities [Cartmill et al., 2016]. To confirm these latest results are the perceptions and satisfaction of consumers for the telepractice services dedicated to patients with head and neck cancer, determined by the high feedback from both patients and doctors. Among the different models examined, the patient's feedback was always positive in relation to the ease of use of the device, the satisfaction of the relationship established with the doctor and the desire to continue using the telepractice modality [Wall LR et al., 2017; Burns C. et al., 2017]. User perceptions are an important fact to consider as, despite the best intentions of treating as many patients as possible via telemedicine, especially in this time of emergency, telemedicine may not be the right model for providing services for all patients. Therefore, patient application criteria must be examined very carefully, as highlighted by the American Speech-Language-Hearing Association (ASHA), application must be assessed on a case-by-case basis for all types of telepractice services, including services for dysphagia. The specific basic criteria for patients with dysphagia and their environment [Malandraki et al., 2011; Ward et al., 2012], concern: the patient's ability to understand and participate in specific procedures for dysphagia (for example vigilance); the stability of the patient's clinical condition; adequate training of the patient and family for all safety and emergency procedures; the availability of adequate bandwidth to ensure a solid Internet connection.

Objective

Our experimental study was born with the aim of implementing qualitatively and quantitatively the assistance addressed to patients with swallowing disorders, with an innovative method, which takes advantage of the opportunities offered by technological progress, to respond to the need for information support in the immediate period following di-

scharge. With SwallowAPP we want to help meet the need for information, associated with posttreatment uncertainty and the psychosocial discomfort that often derives from it. We have focused on aspects that may apparently seem postponed given the health emergency, but, as the patient's needs, represent an urgency to be overcome, to prevent it from generating and degenerating into new emergencies. Finally, we tried to quantify the benefit received by the patient in order to assess how much SwallowAPP can impact on the perception of care received at a time unfavorable to face-to-face relationships. In the same way, we evaluated the ease of use of the system, a fundamental requirement for its acceptance by the user.

MATERIALS AND METHODS

Population

The project was conducted in collaboration with the Maxillofacial and Orl Oncological Surgery Department of the National Cancer Institute "IRCSS - Pascale Foundation" in Naples, in the period between March 2020 and October 2020. The sample examined includes 16 patients aged between 30 and 78 years, of which 13 males and 3 females already known to the hospital for previous diagnosis of squamous cell carcinoma and followed by the Maxillofacial and Orl Oncological Surgery Department for tumor removal by surgical treatment and subsequent logopedic rehabilitation treatment. The total sample was divided into two groups based on the anatomical area affected by the surgical excision. Group A represents the sample of patients with squamous cell carcinoma of the tongue. It consists of 8 patients, of which 6 males and 2 females, aged between 30 and 78 years, with an average age of 55 years, who underwent glossectomy and hemiglossectomy. Group B represents the sample of patients diagnosed with squamous cell laryngeal carcinoma. It is made up of 8 patients, of which 7 males and 1 female, aged between 49 and 68 years, with an average age of 58 years, who underwent a demolition operation of supraglottic laryngectomy. In compliance with the ASHA (American Speech – Language – Hearing Association) guidelines, the candidacy of the subjects for our study was assessed on a case-by-case basis and certain fundamental criteria of patients and the environment were considered inclusion factors, such as: possession general requirements (level of vigilance and attention, state of collaboration, associated communication deficits); stability of the patient's clinical conditions and autonomy in oral feeding, even if modified; adequate training of the patient and family for all safety and emergency procedures. For the purposes of inclusion, a minimum degree of computer literacy is also required: patients, previously training this sample, answered a few questions relating to the use of technology concerning the possession of a technological tool (personal PC, smartphone, tablet) that guarantees Internet connection; the con-

text of use of the technological tool (home or work); the time of use of the technological tool (how many days per week); the activity for which he uses the technological tool (sending e-mails, collecting information, etc.). All the subjects were informed, in depth, about the purpose of the project. The personal data have been processed in such a way as to guarantee security and privacy in compliance with the laws in force on the subject. Pursuant to the law and for the purposes of art. 13, Lgs 30 June 2003 n.196, regarding the protection of persons with regard to the processing of personal data, the information and data collected have been examined exclusively for research purposes. Likewise, the results were used anonymously and solely for scientific purposes.

SwallowAPP

The app project included four different steps: theoretical conceptualization, qualitative training research, the development and finalization phase and finally qualitative piloting.

1) The theoretical conceptualization underlying the birth of this project is represented on the one hand by the observation that mobile apps for smartphones provide an ideal platform for providing educational support to patients; on the other hand, the need for information needs on the part of the population of patients with head and neck cancer. The health emergency has certainly increased the need for information needs, as have the concerns of these patients and their caregivers, who have seen reduced accessibility to the hospitals where they were followed up during the follow-up. Patients who have undergone treatment for head and neck cancer need information and educational support, in relation to the multiple consequences that derive from the different oncological approaches. Their family members have the responsibility of managing the patient: at home the family represents, in fact, the primary network on which the assistance tasks of those affected by disabilities generate a need for continuous care; generally the caregiver is a relative, a friend, the partner, and has to carry out the difficult double task of parenting and assistance. The impact of the care burden on the caregiver's life is absolutely significant: 77.6% of them indicate that, following the care experience, their quality of life has worsened or greatly worsened. The data reported represent an important testimony of the significant role of the caregiver in sharing and implementing the patient's rehabilitation project. In addition, they underline the importance, on the part of health professionals, of dedicating a part of the intervention program to training and supporting caregivers. The burden of care becomes much greater if there are no frequent follow-up meetings and post-discharge checks. The therapeutic diagnostic pathway expresses the multidisciplinary clinical-assistance services that characterize the patient's path in the various phases of treatment and accompanies the patient from the moment of diagnosis, during the hospital stay related to the surgical inter-

vention and up to the time of discharge, as well as in subsequent moments of control and verification of the overall clinical picture. Therefore, the patient is followed both in hospital and outpatient. Due to the complexity of the pathology and the functional, emotional-relational and social implications connected to the clinical intervention, a multidisciplinary team is necessary, as underlined by the Guidelines for the management of the adult dysphagia patient in phoniatrics and speech therapy, drawn up by FLI (2007); the team includes professions with specific knowledge, skills and clinical experience, including training related to counseling and patient approach. An integral part of speech therapy rehabilitation training for dysphagia is counseling, or a relational activity aimed at guiding, supporting and developing the functional skills and resources of patients by accompanying them beyond discharge. In fact, upon resignation, the speech therapist will: draw up the speech therapy budget; consider any interventions specific therapeutics for the planned cancer disorder (radiotherapy, chemotherapy) and their impact on the course of dysphagia; provide the patient with the report on the diagnostic therapeutic path and further information (information brochures, dietary advice, summary of the exercises performed, etc.). In addition, during the follow-up and subsequent checks, through periodic monitoring and speech therapy counseling, the specialist verifies the achievement of the objectives, carries out an analysis of the difficulties and criticalities encountered by the patient to offer possible improvement strategies. All this implies a global and continuous taking in charge, with the need for specific counseling for the patient and his family, aimed at the greater active involvement of the patient in the rehabilitation program. The favorable psychic attitude, facilitated by a correct relationship of trust between health professionals and patients, combined with the subject's motivation, in fact, favor an active involvement, which is essential for optimal functional and social recovery. Specifically for dysphagia, patient and caregiver education is a crucial factor in limiting possible complications. Information and education on the disease and on the right behaviors to adopt, if done with appropriate language and tools, can be very useful for the collaboration necessary to comply with all the prescribed precautions.

2) To improve the healthcare provided, and guide the development of SwallowAPP, qualitative training research was conducted: the most important and relevant concerns of patients and caregivers once discharged were identified through a "review" of the material existing paper, produced by various Italian and foreign clinics. The search for the information patients need was conducted through a review of best practices relating to the most frequent symptoms of patients, the information needs of the same and caregivers as well as the experience of the treatments performed. A thorough literature search was conducted on symptom management in head

and neck cancer. Relevant documents were examined, such as educational manuals, protocols relating to diagnostic-therapeutic-care pathways for dysphagia, management manuals for oncological dysphagia to identify symptoms and best clinical practice interventions to be included in the project. The Rehabilitation Guidelines of the Ministry of Health (1998) state that the rehabilitation and care management, as well as patient and caregiver education, crucial for the reduction of complications, must be planned within the individual rehabilitation project. The project must contain all the information relating to each intervention of the rehabilitation team and must be communicated to the patient and his family in an understandable and appropriate language. According to the evidence-based recommendations of level 3 (non-analytical studies) and level 4 (expert opinion): the team, caregivers and patients should be trained in feeding techniques, with particular attention to postural and dietary modifications, the choice of food, management of behavior and environmental factors, including all preventive activities at the client and caregivers, i.e. on the execution of oral hygiene and management of food preparation (SIGN 6.4); the patient and family members are instructed on the monitoring of signs of penetration and aspiration, as well as the monitoring of the necessary water and food supplies, this to support them in the management of dysphagia, trying to prevent the most feared complications of dysphagia, such as pneumonia, malnutrition and dehydration; the recommendations of the best practice behavior based on the clinical experience of the guideline development group (Good Practice Points), argues that the administration of drugs must be guaranteed to patients who cannot take anything orally or who are on a modified diet, with appropriate information to the personnel in charge (SIGN 2.2.1). In preparation for the development of SwallowAPP as an appropriate resource for patients with head and neck cancer, we referred to a study, as well as to characterize the information needs of patients (previously exposed results), also to describe the preferred formats and the timing for receiving such information. The results show that patients generally prefer to receive information in a format that can be viewed at will, available or accessible from home (such as brochures, DVDs, or programs on the Internet). With regard to the timing for receiving information, it can be deduced that the information need on the part of these patients is important throughout the entire course of treatment: 39% of them wished to receive information programs upon diagnosis; 31% wanted such programs during treatment and 34% preferred this information during the one to three month period after treatment. A small percentage of patients were instead interested in receiving this information more than three months after treatment [Carolyn Y. Fang et al., 2012].

3) After the scientific research phase we moved on to the development and finalization phase of Swal-

lowAPP. It is a web-app (from English "web application", in Italian "web application"), ie a link always available online, which does not require any installation, nor therefore access to the stores of the various platforms. However, it is possible to create a shortcut on the desktop of the computer or on the home screen of a mobile device, so that it can be installed on all operating systems and on all devices: a single link is therefore enough that allows you to be present on all platforms. Another point in favor concerns the resolution of security flaws: in the case of native apps, these can only be solved by downloading a new version or an update, while a web application is not subject to personal updates, as the necessary security updates they are made directly to the software, so that all users can automatically access the more secure version. In addition, the overall costs for web apps are lower and are created faster. The version of the app provided at the end of the development process has two sections: the first general, in which it is possible to have access to the contents and a section for dialogue with the user. The general part has been organized into different modules, the patient can freely click on the appropriate icon and have access to the information contained. First module: contains the previously outlined theoretical motivations that led to the birth of the project, with particular reference to the importance of patient and caregiver education in relation to some precautionary behaviors to be implemented during meal assistance. Furthermore, the objectives of SwallowAPP are explained here. Second module: here it is possible to receive information on physiological swallowing and its alteration, dysphagia, in order to increase the understanding and awareness of one's difficulties, and to be able to recognize the symptoms that characterize it early. In addition, this section offers a presentation of the multidisciplinary team essential for the management of dysphagia, so that the patient recognizes any emergency promptly and know, if necessary, who to contact. Module Three: Dysphagia can induce a range of potential health risks, including an increased chance of malnutrition, dehydration, pulmonary complications and death. However, dysphagia itself rarely causes death, while these morbidity factors can be associated in various ways to determine it. It is therefore of fundamental importance that the patient first of all knows what the complications of dysphagia are and that he is informed on the methods of prevention and management of the latter. In this way, attention to the problem is increased, reinforcing the baggage provided with the counseling activity carried out previously, as well as adherence to the recommendations. Fourth module: this part is the one that best responds to the most relevant and concrete concerns that affect the caregiver in particular when returning home. Caregivers who are educated on the patient's difficulties and the risks they face, can here find stable and immediately available information regarding the precautions to be implemented daily before and during meal assistance. Each patient will find gene-

ral information on specific diets, on the changes to be made to foods and on which foods are recommended and which ones are risky. Where the patient needed more specific indications, these will have been offered at discharge and the patient knows that any changes will always be discussed with the specialists. This section also provides general advice, not directly related to the meal, such as the importance of oral hygiene and guidelines for taking medications, behavioral rules, specific postures and characteristics of the environment necessary during meal assistance. Fifth module: this section is especially specific for patients with head and neck cancer. Some patients, in addition to the more general information presented in the previous modules, require further information. Here are listed the swallowing difficulties that are possible to encounter after surgery of the upper respiratory-digestive tract, as well as the acute and chronic toxicities related to radiation and chemotherapy treatment. In addition, the methods for managing any enteral nutrition, the management of the tracheal cannula, which can remain even after discharge from the hospital and which require particular assistance from the caregiver, are also shown, who must therefore be appropriately polite.

This information support offered by SwallowAPP is advantageous compared to a paper support, as the latter is perishable, can be lost, is not interactive, and can be consulted by a limited number of people for each patient, unless reproduced on paper. Through SwallowAPP, the patient can, on the other hand, easily and immediately access the information sought, at different times and places, using the mobile network. The choice of language used was calibrated on the basis of usability by patients. It is a little technical language but precise, simple and direct. Finally, given the general tendency to search the web in an often inappropriate way for information relating to the disease, a section has been created in which links and sites have been inserted, concerning for example the aids and the different recipes, appropriately viewed and selected to facilitate the research ensuring the quality of information. SwallowAPP is not static, it is a patient tool that will be continuously updated to be really used as a daily support: the patient is given the opportunity to fill in the daily food diary to better manage the meal time and to have feedback on the progress over time, relating to the quantities of water and food consumed, and the conditions in which the meal takes place, so as to have under control the major potential risks associated with dysphagia and nutrition. Particular attention is also paid to monitoring various aspects that influence the quality of life, first of all the pleasure of a meal. From the description so far exposed about the theoretical assumptions and contents of SwallowAPP, it is possible to state that it is not a medical device as all the functions are oriented towards patient education, with the aim of providing greater awareness, education and empowerment, and not for the purposes of diagno-

sis, cure, treatment, prevention of disease or other condition. The need for direct consultation with the reference specialist is therefore frequently stressed. Through SwallowAPP the patient can, in fact, request to contact the members of the team through an icon that represents the possibility of writing an e-mail, giving a specification on the request, being able to attach photos or files. The patient can also specify the urgency of his request through a color and will be contacted no later than 24 hours. It is a software that can certainly be used in the healthcare environment, in clinical care and in patient management: it supports patient-centered healthcare, but does not need to be regulated by the FDA. [FDA Industry and Personnel, 2019].

4) For the piloting of SwallowAPP we evaluated the usability and feasibility of the app through a detailed qualitative and quantitative analysis of the data reported by patients. In order to quantify the impact that SwallowAPP has on the perception of the care received, the Swal-QOL and Swal-CARE questionnaires by Colleen A. McHorney, (2000) were administered. Both questionnaires represent a step towards achieving a precise goal, i.e. a synergistic and complete compendium of tools for specific health outcomes for dysphagia and which at the same time represent a balance between the clinician-guided parameters and those concerning the perspective of the patient. After its creation, Swal-CARE was separated from Swal-QOL, as it may take more than one visit for patients to be able to reliably assess their doctors based on quality of information and advice and satisfaction of their attention, while Swal-QOL could be completed on or before a first visit. All patients were subjected to the "Swallowing quality of life" (Swal-QOL) test for a first approach with the patient and to understand how much his swallowing disorders affect her quality of life on a daily basis. It features 44 simple questions, organized into 11 domains: Social Impact (IMP), Meal Duration (DUR), Desire to Eat (DES), Symptoms (SIN), Food Choice (SCE), Communication (COM), Fears (PAU), mental health (MEN), social functioning (SOC), fatigue (FAT), sleep (SON). To complete the questionnaire, the patient is asked to indicate a number from 1 to 5 for each item to express what he feels about the above: 1 (very true), 2 (quite true), 3 (rather true), 4 (not much true), 5 (not true). The correction of the questionnaire provides for the sum of the scores obtained in each single domain separately, allowing you to immediately understand the aspect that most affects the quality of life, a higher score indicates a better quality of life. The Swal-CARE questionnaire used to evaluate the perception of the care received, in terms of information provided by the reference speech therapist and satisfaction for the dedicated attention, it consists of 15 elements that evaluate the quality of care and patient satisfaction. The first 11 items investigate the patient's assessment of the information received in the various fields of interest (IND): foods and drinks recommended for the pa-

tient; foods and drinks that the patient should avoid; techniques that help the patient to swallow; techniques to prevent food from going sideways; knowing when to contact the swallowing specialist; treatment goals for the swallowing problem; possible treatment alternatives; what to do in case the food goes sideways; signs indicative of malnutrition and dehydration. The patient is asked to indicate a number from 1 to 5 for each item, to evaluate these indications as: poor (1), sufficient (2), good (3), very good (4), excellent (5). The last 4 items investigate the patient's degree of satisfaction in relation to her impressions, positive or negative, on the intervention received by the swallowing specialist (SOD): patient's trust placed in the swallowing specialist; explanations received from the swallowing specialist about the treatment performed; time devoted to the patient by the swallowing specialist; the swallowing specialist places the patient's needs as a priority. The patient is asked to indicate for each item a number from 1 to 4 to express his impressions: never (1), sometimes (2), frequently (3), always (4). For the Swal-CARE correction, the results obtained in the two areas are summed separately for a maximum of 55 points reachable in the indications section (IND), and a maximum of 16 points in the patient satisfaction section (SOD), also in this case. a higher result is indicative of a better perception of the care received. Finally, we wanted to quantify the usability of SwallowAPP by our sample, using the modified System Usability Scale (SUS). We have chosen to use the SUS, proposed by John Brooke in 1986, as a usability testing tool as it is a widely used generic measure of product usability: it is a free, simple, questionnaire-based scale to be answered. very fast, it is versatile (it can be used to evaluate websites, software, mobile devices and medical systems), suitable even when applied to small samples (N < 14) and has excellent reliability. The SUS contains 10 questions (questions 1, 3, 5, 7 and 9 are positive and questions 2, 4, 6, 8 and 10 are negative) based on the five-point Likert scale, on this scale the subject will have to express whether strongly disagrees (1) or strongly agrees (5) with respect to the content of the item. A higher SUS score indicates better usability of the product.

Swal-QOL results

The Swal-QOL and Swal-CARE questionnaires were re-administered to all patients in T2, 30 days after discharge. From the comparison of the results with respect to the administration of the Swal-QOL questionnaires in the time T1, that is in the moment immediately following the discharge and in the time T2, that is after the use of the app, it emerges that in T2 the quality of life has improved for the whole. patients belonging to both groups in all domains. However, a greater percentage increase was found for five domains: the personal impact that investigates the difficulty of managing the dysphagia problem for the patient and the concern it entails (IMP); the desire to eat (DES); food selection (SCE); fears of choking while eating or drinking, of

having pneumonia and of recognizing these risks early (PAU); mental health, that is, feelings of depression and impatience, feeling frustrated and annoyed at having to pay so much attention at mealtimes (MEN).

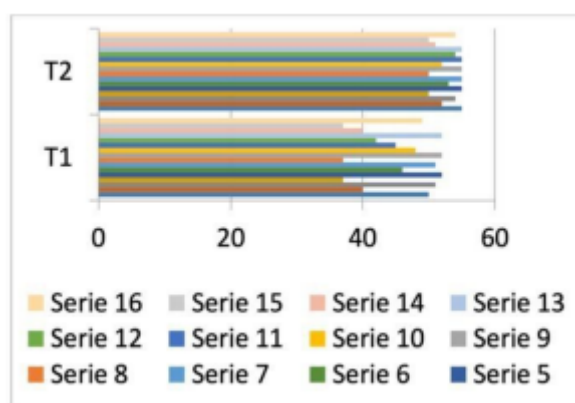
Swal-CARE results

Table 1

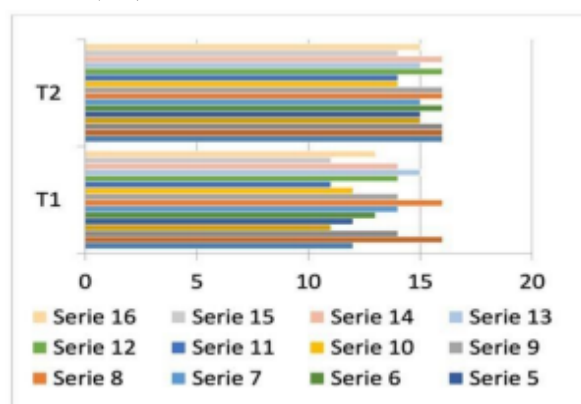
	(IND)		(SOD)	
	T1	T2	T1	T2
1.	50	55	12	16
2.	40	52	16	16
3.	51	54	14	16
4.	37	50	11	15
5.	52	55	12	15
6.	46	53	13	16
7.	51	55	14	15
8.	37	50	16	16
9.	52	55	14	16
10.	48	53	12	14
11.	45	55	11	14
12.	42	54	14	16
13.	52	55	15	15
14.	40	51	14	16
15.	37	50	11	14
16.	49	54	13	15

For the purposes of our study we have focused more on the analysis of the results obtained by patients in the Swal-CARE questionnaire, shown in table 1. We can see an increase in the scores over the time interval (T1-T2) both relative to the area of indications (IND), both with regard to patient satisfaction (SOD). In the Swal-CARE questionnaire, the score for the indication section can vary in a range between 11 (poor indications) and 55 (excellent indications). As can be seen from graph 1, there is an almost evident evolutionary trend in the perception of the qualities of the indications received from T1 to T2. The patients are mostly aligned with the exception of seven anomalous lines (pcs. 2,4,6,8,10,14,15) which are visually different from the others. Such patients conform very low even in T1, however, after 30 days of discharge they show a significant recovery. The results of all patients obtained at T1 fall within a range of 37-52, with an average of 45 for which most patients rated the indications received in that period as good to very good. At T2, all subjects show an increase in results by evaluating the indications received through the app as very good - excellent, with results ranging in the range of 50-55, with an average of 50. In the Swal-CARE questionnaire, the score relative to patient satisfaction can vary in a range between 4 (never) and 16 (always). Even in the case of patient satisfaction, as for the indications section, the evo-

lutionary trend from T1 to T2 is visually evident from graph 2. In fact, the maximum result at T2 was reached by eight lines (pcs. 1, 2, 3, 6, 8, 9, 12, 14), while at T1 only two lines (pcs. 2 and pcs.8) reach this result. From the graph it is possible to deduce that in T1 three lines (4,11,15 pcs) negatively assessed their impressions of the surgery received, however, in T2 there was a positive re-evaluation by these patients of their impressions of the surgery received. The results of the total patients in T1 are arranged rather unevenly in a range between 11 and 16, with an average of 13. The results of the same patients, in T2, 30 days after discharge, are distributed much more homogeneous and oriented towards the right, the range goes from 14 to 16 with an average of 15. This last result indicates that most patients have positively evaluated their impressions of the intervention received. Furthermore, we have individually examined the individual sections of the two parts that make up Swal-



Graf. 1: (IND)



Graf. 2: (SOD)

in order to investigate in a more precise and specific way which are the aspects that have received the greatest benefit from the indications obtained through the use of SwallowAPP. and to detect the aspects that, despite the targeted intervention, affect patient satisfaction. In Table 2 compares the sum of the individual results obtained by all the patients at time T1, in the moment immediately following discharge, and at time T2, 20 days after the first administration of the test, a period during which they used the SwallowAPP system. The results of the individual areas are represented, both with respect

to the evaluation of the information received before and after the app, and about the positive and negative impressions on the intervention received from the time of discharge at T1 and subsequently the use of the app. The results that evaluate the indications received from the patient show an increase in the scores relating to the areas they concern: indications about the foods and drinks that are recommended for the patient and those that the patient should avoid taking (IND1, IND2, IND3, IND4); indications to be able to identify the moment in which it is necessary to contact the swallowing specialist (IND7); indications to be able to detect indicative signs of malnutrition and dehydration (IND11). With respect to patient satisfaction, the results show a greater number of positive impressions on the surgery received in the last 20 days, in two sections: trust placed in the swallowing specialist (SOD1); time that the swallowing specialist devoted to the patient (SOD3).

Recommended Foods (IND1)	T1 59 T2 75
Foods to avoid (IND2)	T1 45 T2 78
Recommended beverages (IND3)	T1 38 T2 60
Beverages to avoid (IND4)	T1 59 T2 71
Techniques to facilitate swallowing (IND5)	T1 70 T2 72
Techniques to prevent food from going sideways (IND6)	T1 72 T2 75
When to contact the specialist (IND7)	T1 52 T2 70
Objectives of the treatment (IND8)	T1 73 T2 75
Possible treatment alternatives (IND9)	T1 68 T2 69
What to do if food goes sideways (IND10)	T1 47 T2 53
Signs of malnutrition and dehydration (IND11)	T1 45 T2 78
Trust placed in the specialist (SOD1)	T1 55 T2 64
Information provided by the specialist about the treatment (SOD2)	T1 54 T2 56
Time dedicated to the patient by the specialist (SOD3)	T1 47 T2 64
Priority of the patient's needs for the specialist (SOD4)	T1 57 T2 62

Table2

SUS results Over time T2, patients were asked to fill out an additional questionnaire, namely the system usability scale (SUS) used to evaluate the usability, in terms of efficiency, effectiveness and usefulness of our web-app. Table 3 shows the results obtained by the patients relative to the administration of the SUS scale, from these results we will be able to deduce the degree of acceptance of SwallowAPP by users. An SUS score above 68 is considered above average and any value below 68 is below average. So all patients considered the system acceptable.

	System Usability Scale (SUS)		System Usability Scale (SUS)
1.	70	9.	96
2.	72	10.	75
3.	80	11.	85
4.	84	12.	76
5.	75	13.	85
6.	90	14.	94
7.	79	15.	93
8.	85	16.	78

Table 3

DISCUSSION

With the data collected, the analysis of the results carried out shows that: all patients expressed an increase in their quality of life at time T2 compared to time T1 through the administration of the Swal-QOL questionnaire. An increase in results over the same period of time was also found through the administration of the Swal-CARE questionnaire used to assess the perception of the care received for the swallowing disorder, both in relation to the area of indications and patient satisfaction. The greatest increase in results 30 days after discharge, relating to the indications received by the speech therapist, was detected in the sections of the knowledge of food and drinks that the speech therapist recommends to the patient and those that, on the contrary, the patient must avoid take in order to swallow more easily and safely. Therefore, the Swal-CARE questionnaire shows that SwallowAPP has a considerable impact on the perception of care in relation to the "indications" area. However, the scores regarding the indications about the compensatory postures and the swallowing maneuvers that help the patient to swallow, did not show a great increase following the use of SwallowAPP, as they were already high at the time of discharge as desired by the speech therapist. It is possible to give an explanation to this result from the observation that all patients, already in the period prior to discharge, receive a broad description, through direct speech therapy training, regarding any compensation maneuvers, while there may not be the time necessary to give the patient detailed information on all recommended foods and foods to be avoided, as present in SwallowAPP. The literature reports that the major concerns of patients and especially caregivers when returning home are related to when assisting the meal, so also the methods of food preparation, changes in consistencies and the choice of foods to be taken safely. Through SwallowAPP it is possible to have access to real very large lists of recommended and forbidden foods, as well as practical advice aimed at preparing them, in order to expand the possibility of choosing a safe food in relation to the

dysphagia problem and to the same time that respects the patient's taste and desire to eat as much as possible, with a view to safeguarding the hedonistic aspects of food and nutrition. Results equally increased were found with regard to identifying the time when it is necessary to contact the swallowing specialist and recognizing the signs of malnutrition and dehydration. It is possible to deduce that the broad description of the complications that these patients may encounter, the clear exposure of the related related symptoms and the signs to which particular attention should be paid in order to prevent dreaded complications, present in SwallowAPP, have been highly appreciated by patients. Through the Swal-QOL questionnaire, the latter expressed fewer feelings of fear related to the time of the meal and improved their attitude in relation to the swallowing problem, reporting feeling less annoyed, discouraged, frustrated and impatient to lend in this way. a lot of attention to one's diet. Finally, with regard to patient satisfaction, a greater number of positive impressions were found in T2, compared to the trust placed in the swallowing specialist and the time that the latter has dedicated to assisting him. These results achieved are of fundamental importance for the purpose that SwallowAPP aims to achieve: raising awareness of the patient with respect to the recognition of the symptoms and signs of complications of dysphagia, as well as dysphagia itself, also a symptom. In this sense, SwallowAPP is an extension of personalized medicine that aims at prevention, adherence and patient participation in what it includes communication functions for the doctor-patient relationship and stimulates the psychocognitive aspect, which plays a significant and unique role in how an individual experiences such devastating emotional events, copes with illness and makes decisions about their health. However, it was not possible to give the patient the opportunity to register and create their own personal profile as this would have entailed the risk of misappropriation of data or disclosure of sensitive patient data. We expect this to be a challenge that the healthcare system digitalization device industry can accept and solve for improve the effectiveness of the system through greater customization. In line with the results offered by the literature regarding the readiness of the population with cancer in the head and neck district to adopt telepractic models for the provision of health care, from the results obtained from the administration of the SUS scale, it can be inferred that most some patients consider SwallowAPP to be an easy-to-use system that can be used independently without too much difficulty. By comparing the data relating to the variables of sex, age of patients, and computer literacy, it is possible to deduce that these do not significantly affect the use and the advantage gained by SwallowAPP.

CONCLUSION

The study conducted on patients also supported by SwallowAPP has shown that implementing the quality of care provided to the dysphagia cancer patient during the early stages of follow-up following surgery, also had a strong impact on the patient's quality of life. always considered a priority by the clinician but not easily pursued given the strong psychosocial impact that dysphagia determines in these patients, even after the success of cancer treatment. To achieve optimal swallowing function in this patient population, speech therapist intervention is essential in a continuum of care, from rehabilitation to long-term survival. The nature of the specialist speech therapy intervention may vary along this continuum, based, above all, on the needs of patients at the various moments that characterize the treatment. As well as the needs of the patient over time, so the way in which the assistance service is provided may vary. SwallowAPP was used by our sample of patients on an experimental basis. It will soon be accessible to all users (patients, caregivers and clinicians) who are interested; it is emphasized so much to the patient, so much in the presentation of this work that his goal is to be exclusively an associated support to traditional assistance, so your reference specialist must always be consulted. However, before this happens it is necessary to administer the Mobile Application Rating Scale, the

only reliable measure of the quality assessment of health apps and the only tool that can guarantee the reliability of SwallowAPP, as both the US and European jurisdictions apply their own regulations. exclusively to medical apps that diagnose and treat diseases, while all apps with education and information features, such as SwallowAPP, will not be affected. As hypothesized in the initial stages of our work, which occurred in the midst of the health emergency, the latter unfortunately seems destined to last for a long time. So today it is still necessary to optimize and, if possible, resize the flows of patients in healthcare facilities. The tool presented was found to be appreciated by patients; future goal is to expand the sample of recipients and evaluate the effectiveness even in further moments of the long follow-up to which these patients undergo. At the same time, we hope that SwallowAPP can also represent an opportunity and a valid tool for the clinician to facilitate, increase and expand its support work for patients and their families. In this particular historical period, we hope it will represent a further protection tool for both patients and operators. With the use by an increasing public and the recording of the relative feedback, the project aims to optimize the potential of this tool by imagining it as a valid support even when the health emergency will no longer impact so strongly on the rhythms and methods of provision of rehabilitation services.

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