

A Therapeutic Education Program for patients that underwent at temporary tracheotomy and total laryngectomy: leading to improved the “Diagnostic, Therapeutic and Assistance Path”

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Abstract. *Background and aim of the study:* Therapeutic education helps patients with a chronic disease to acquire and maintain the ability to live their life while handling their illness. Patients with temporary medium-term tracheotomy or permanent tracheostomy need to acquire skills to be able to handle the stoma, tracheal tube, related issues, and other apparatuses. This was the purpose of our therapeutic education program, which was aimed to take patients and caregiver to an efficient level of self-care. *Methods:* In 2018, was created a CME-accredited (Continuing Medical Education) “Workplace-based Learning Project” involving all the nurses in the Otolaryngology Head and Neck Operational Unit, along different specialists on the Disease Management Team, thereby forming an “Improvement Group”. We established parallel workgroups for bibliography research on data-based like PubMed, Cinahl, Cochrane, Google scholar, in order to obtain the information to write up a shared document. *Results:* We wrote out an Operational Protocol which lined up nursing skills – when handling patients with medium-term tracheotomy or tracheostomy – with scientific evidence. Our standard educational plan (customizable, based on each patient’s characteristics) promote the patient’s learning with respect to self-care. *Conclusions:* This project has set the basis for the improvement of the quality of assistance given to the patients and therapeutic education provided them. It has encouraged the development of the skills of the nurses involved, along with their motivation, and their integration on the Disease Management Team. But, it will be necessary in the future to further evaluate the effectiveness of the program in terms of self-care. (www.actabiomedica.it)

Key words: Therapeutic Education Program, self-care, nursing skills, workplace-based learning, tracheotomy, tracheostomy and laryngectomy

Introduction

At this moment in time, health services are experiencing increasing demands for assistance. This reflects the fact that people are living longer, often to advanced old age, accompanied by chronic health problems (1, 2). This evolution led to reflection on the various aspects of nursing and care-taking entities with respect to the

professional skills which enable them to respond in an appropriate manner to the needs of their citizens (2).

Due to the above, attention now shifts from the hospital, which handles acute cases, to locations which deal with chronic stages. The medium and long-term problems found here create the need for an integrated care pathway which connects them (2). In the intensive care hospitals the acute phases are treated. They

are a resource to be used only when strictly necessary. This is where the patient, with his/her specific health problem, is taken into charge to face his/her specific pathology by an integrated multidisciplinary team.

With this model, a different response mode comes to the fore. Appropriate technologies and skills provided by the appropriate quantity and quality of personnel are assigned in differing degrees to clinical instability and its accompanying complexity in terms of assistance. This combination gives the patient the most appropriate and timely of responses (2-4).

In this setting, a Diagnostic-Therapeutic-Assistance Path standardizes processes using scientific evidence. It is designed to ensure professional integration and coordination, guaranteeing adequate and equal clinical outcomes, even though it does not depend wholly on professionals. Each professional, with his/her own specific competences, contributes to achieving the patient's goals, which have been identified in a shared manner (1-5).

Thus, it becomes essential to involve the patient in the decisions that concern him/her (1, 2, 5, 6). Carrying this concept further, investment must be made in the patient's therapeutic education. This then becomes part of the process which helps sick people acquire and maintain their ability to best conduct their own lives while living with the illness itself. This, in turn, enhances the effect of other therapeutic effects derived from other sources (5, 7).

The patient's family is also encouraged to participate. The context of the patient's lifestyle and experiences is also considered. And content is designed to stimulate learning how to promote empowerment and efficient self-care especially when dealing with chronic illness(5). This outcome is central to nursing assistance, and it encompasses the other goals (8).

In this manner, therapeutic education becomes a fundamental process in a structured health context. The multidisciplinary team, on a clinical assistance path with case/care management, places the patient (and his/her specific condition) at the center, while the related outcomes to pursue are studied (5). This involves the entire professional team. They interact in a focused way to guarantee coordinated and timely assistance, thereby increasing patient satisfaction and the effectiveness of the services (5).

Middle-Range Theory for Self-Care in Chronic Pathologies analyzes the characteristics and the factors necessary to make it efficient. The goal is to enable the patient to:(9)

- Better understand his/her illness, treatments, and complications
- Handle his/her new condition in a competent way, having been given info and knowhow
- Avoid complications by reforming existing behavior modes

Scientific literature has shown that training that employs active involvement, can produce better results in terms of learning and provide positive practical effects. For this to occur, three essential elements are involved: concrete problems to resolve, interactivity, and direct involvement in favorably organized contexts (10). In optimal situations, one's own work context provides both training needs and satisfaction (10).

To support this, in 2003, the CME (Continuing Medical Education) National Commission introduced what was called "Workplace-based Learning". This was a new mode that totally integrated the work environment and clinical-assistance procedures. As a result, the added value was actually determined by a motivational push which led professional into carrying out individual or group investigations/research, finding solutions for concrete problems (10).

"Workplace-based Learning" emerged from an intentional and well-organized search for solutions to real problems. And since its origins lie in real problems, monitored over time, it is clear that the evaluation of organizational change is as decisive as the learning process. And therefore, project methodology must be rigorous enough to guarantee the quality of the results while maintaining the right flexibility for the context (10).

One way to carry out this type of training uses "The Improvement Group". This was created to show the concept of change and multidisciplinary training in one's own work environment (10).

"Improvement groups use multi-professional and multidisciplinary activities in the workplace to promote health; the continual improvement of clinical assistance, management, or organizational processes; and the consequent accreditation or certification of the health structure involved. Here the learning process

occurs through the integration of a group of equals.” (10, 11)

Improvement groups give operators responsibility for their own training (self directed learning), thereby encouraging colleagues to reflect upon their own work. Exchanges and reciprocal learning are promoted by sharing. Though always retaining methodological rigor, this mode encourages the possibility of incurring changes in the overlying organization. It enables it to meet the needs of the professionals involved, thereby encouraging their participation (10).

The process used to design, implement, and carry out an improvement group is divided up into the following phases (10):

1. Once a problem is identified along with the corresponding aspects that need to be faced, the head of the project writes out a program which identifies goals, participants, work phases and their duration, and a way to evaluate the project's success. Then he proposes it to the training service.
2. This document is then evaluated by a special multidisciplinary and multi-professional committee consisting of health professionals who then guarantee its appropriateness.
3. Once modified or approved by the committee, the project may start.

The head of the project must guide the work done by the participants, assign responsibility, and work on making the project transferrable, watching out for the effects. In addition the head formulates the final report, giving extra credit to those whose efforts stood out.

Training of this type – fine-tuned starting from 2005 by the Training Service of the Azienda Sanitaria Provinciale in the Province of Trento – was then initiated in 2017 at the San Martino Polyclinic Hospital in Genoa. Its usefulness was revealed as a way to focus on skills, performance, and health successes regarding the patient (10).

Method

In agreement with the considerations described above, our project was designed for Otolaryngology Head and Neck Unit of the San Martino Polyclinic

Hospital (Genoa, Italy). It used workplace-based learning carried out by an improvement group, and it was conducted by the nursing referenced to the Diagnostic-Therapeutic-Assistance-Path for the oncologic head neck disease, who worked with the other members of the multidisciplinary team.

Patients who undergo open surgery, which creates medium-term temporary tracheotomies or permanent tracheostomies, need to be provided with specific skills which allow them to handle – on their own – the stoma, the tracheal tube, and all that which is affected by this and other devices, to guarantee air passage in their airways and prevent the onset of complications.

A customized therapeutic education program was set up to take patients and their related caregivers to the point of efficient self-care. Up till now, there had been no clear operational methodology which defined the contents, instruments, methods, times, places, actions, and roles involved, and so, this lack of standardization also made it difficult to track and records the outcomes. Confirming this, both the day clinic nurses who participated in check-ups and follow-ups after the patient was released, and the speech therapists who then worked with this type of patient, noted the patients lacked ability for self-care and needed for further explanations.

The most critical phase has been identified as that immediately after discharge. This is the point where patients leave a protected environment – inside of which they are safe and receive answers to all their needs – to reenter a context in which they must measure themselves against their own ability for self-care and management. And yet, these abilities are consolidated only by continual practice and the gradual acquisition of experience.

As a result, the therapeutic education carried out in the recovery phase, needs to be as complete and efficient as possible. It must focus in particular on the prevention of more serious complications (i.e. airway obstruction, infections, and hemorrhages).

By planning early and providing follow-up meetings with discharged patients, we have found that this can help them and their caregivers to acquire additional skills and greater confidence. This in turn allows the health professionals to monitor their learning process and intervene in an appropriate manner where necessary.

Patients need to be able to take care of their daily needs, carrying out the main procedures in a safe and efficient way. Additional educational can then be given on an outpatient basis, and its evolution can be monitored over time. The educational program that we designed serves to reach this goal.

But there is a difference in the training to be given to a patient who underwent temporary tracheotomy versus a patient with a tracheostomy, after a total laryngectomy. This is due to the fact that while a tracheotomy is temporary, the latter modifies permanently the upper respiratory airways. Thus, in the first case, autonomous management is more limited. Professional experts intervene in the execution of some risky maneuvers, done in the hospital. The opposite holds true with regards to total laryngectomy. In this case, the patient learns to handle and live with it, turning him/her into the main subject of the therapeutic education program of self-care.

Our goal was intended to draw up an educational project using this scenario, an intermediate phase with respect to the whole process. And only after having done so, we would create a data bank which verified the efficiency of the training program provided.

The project was divided into five phases. The **first phase** directly involved the coordinator of the Otolaryngology Head and Neck Unit of the San Martino Polyclinic Hospital in Genoa Italy and her promoter. It provided a detailed educational plan which was shared with the Chair of the Operational Unit and with the Director of the Health Professions Operational Unit.

The project was presented in December 2017 to the Scientific Committee through the Simple Departmental Structure for Training and Communication to enable a training program that would be accredited by Continuing Medical Education, carried out in accordance with its “Workplace-based Learning” methodology. Approval was obtained in February 2018.

In March, the head (and coordinator) of the project, along with a representative of the nursing group, attended a course designed to supply methodological support for the development and implementation of this type of program. This involved teaching experts and support from a distance. Once the training was completed, the project was begun.

A work team was set up as an “Improvement Group”. It consisted of 25 nurses, and 13 DMT (Disease Management Team) specialists for oncologic pathologies in the cervico-facial district (two otolaryngologists, a radiotherapist, an oncologist, two psychologists, a physiatrist, a physiotherapist, two speech therapists, two dieticians, and a health assistant), actively working as experts. It was also involved a nurse infection control.

Though well aware that the number of participants was rather high, it was decided to involve the whole nursing group, the principal students from the training course subjected to the proposed project, in order to permit the latter to become a source of motivation, producing consolidation/development of skills through the training.

In this specific context it is, in particular, the nurse who works the most to activate the educational program with the patient and/or caregiver.

Seeking our goal in self-care terms, we felt that it was necessary to work on the updating of nursing skills with regards to recent scientific research when dealing with patients with tracheotomies or tracheostomies. We also felt it necessary to plan and extend the program of therapeutic education by specifying its subject, methodology, and tools. A major role was also played by dieticians and speech-therapists, working more independently. The time required for each of these, including nursing, was 25 hours in total.

The **second phase** was begun in April 2018. It established three secondary groups of nurses, working in parallel, who researched:

1. Scientific evidence regarding the handling and the necessary devices for tracheotomy-tracheostomy.
2. Therapeutic education concepts and related methods, along with the identification of tools for recording educational actions that have been carried out and an evaluation of their effectiveness in teaching the patient/caregiver, the concept of self-care, and the quality of life for patients who have undergone tracheostomy.
3. Brochures and booklets providing information for laryngectomized patients, in order to write a specific booklet to be given to the user and/or caregiver at the same of the learning period.

These groups worked independently, though under the guidance and supervision of the head and coordinator of the project. Some work was done at home, and then discussed with the group.

Databases like PubMed, Cinahl, Cochrane, Google scholar, were consulted. The key words we selected were: “tracheotomy”, “tracheostomy”, “tracheostomy management”, “laryngectomy”, “tracheostomy tube”, “tracheostomy guidelines”, “laryngectomy management”, “tracheostomy care”, “laryngectomy tube”, “pneumonia infection”, “suction”, “suction management”, “self-care”, and “patient education”.

As for point 1 inclusion criteria have been: documents both in English and Italian, covered the years from 2008 to 2018, and all dealt with adult patients. 10 guidelines were analyzed, along with 2 operational protocols, 1 policy, 1 procedure, 7 articles, and 3 manuals. We did not include publications which did not provide detailed procedures for the handling of tracheotomy-tracheostomy or those which did not seem pertinent (Table 1, Figure 1).

As for point 2 inclusion criteria have been: publications, both in English and in Italian, dating from 1998 to 2018, that discuss therapeutic education, self-care in general, and tracheostomized patients and their relative quality of life.

We consulted 5 books, 1 guideline, 3 operational protocols, 18 articles, and 1 training program for educators. We excluded documents which describe educational methodologies that were not very applicable in our specific context of reference. We did not use those that were too generalized, and texts that did not focus directly on patient learnings (Table 2, Figure 2).

As for point 3 just a few booklets were consulted, without doing an in-depth search, because we had decided to write our own. Our booklet would discuss basic subjects and supply useful information that our patients, having undergone a total laryngectomy, would need.

The product of the work groups' research was shared on many occasions. On the basis of the data that emerged, we made decisions regarding the next phases to be taken, until a final document was approved by all.

The **third phase** began in May 2018. It expanded up an operational protocol which included both skilled

procedures for the nurses handling a tracheotomy-tracheostomy and the therapeutic education program for the patient or his/her caregiver in the recovery phase. A booklet for the laryngectomized patients was also written to be provided them at the start of the training program. These tools were the specific goal of the training project, and will be described in detail when we speak of results.

The experts involved in this phase were various specialists from the Disease Management Team. They were chosen on the base of their subject and specific competences, and greatly helped us write out the information material given to the patient. Each specialist contributed with his/her specialty. The final documents were then shared among the operators.

The **fourth phase** was begun in September 2018. In this phase, both the Chair of the Otolaryngology Head and Neck Unit and the Director of the Health Professions Unit checked and approved the operational protocol and the information booklet. Publication on the official website was requested after an evaluation carried out by the Clinical Risk Management Unit, Quality Accreditation, and Public Relations Office.

The **fifth phase**, started in January 2019, is still ongoing, and involved the application of the operational protocol created.

Results

The guidelines and the operational protocols that we chose were considered to be specifically instituted for tracheotomy-tracheostomy, and provided detailed information for the various procedures. These documents were carefully evaluated and from those were extracted our operational protocol described below.

With regards to the theme of therapeutic education and self-care, we selected documents which provided definitions, methods, tools, and variables which could affect results. We also considered articles related to the quality of life of patients with tracheostomy. Our research found only two instruments to register the occurrence of educational interventions, and none related to the traceability of the self-care level evaluation.

Four instruments were found to evaluate the skills of health service operators for the various procedures

Table 1. Records selected related to Tracheostomy management

N.	Authors	Title	Record	Source and Date
1	ACI – NSW Agency for Clinical Innovation – ICCMU – Intensive Care Coordination & Monitoring Unit. <u>Guideline Owner:</u> NSW Agency for Clinical Innovation <u>Primary authors:</u> Chaseling W. <u>Guideline Management Team</u> Chaseling W., Bayliss S.L., Rose K., Prof. Davidson P., Armstrong L., Boyle M., Chung C., Caldwell J., Griffiths K., Johnson K., Lowe S.P., Reddy N., Thackray N., Zimbiti C.	Suctioning an Adult ICU Patient with an Artificial Airway: A Clinical Practice Guideline	Guideline	2014 https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0010/239554/ACI14_Suction_2-2.pdf
2	General Direction S.I.T.R.A, Regione Lombardia, ASL Brescia. <u>Manager:</u> Dr. Di Meo S. SITRA ASL Brescia. <u>Working groups coordinator:</u> Crescini L. - SITRA - ASL Brescia <u>Working group:</u> Agazzi C., Baruffaldi S., Bertozzi E., Bianchetti S., Di Benedetto F., Fappani M., Fiorini J., Luvriti C., Franzini M. A., Guarneri S., Menchi V., Pollini S., Roberti O., Shaban Y., Venturi A., Festa G., Foglia V., Gaia M., Leali R., Raccagni M., Romagnoli P., Sbaraini C., Beruffi M. S.	L'assistenza e l'intervento educativo alla persona portatrice di cannula tracheale [Assistance and training for the patient with a tracheal tube]	Operational protocol	December 2011 https://docplayer.it/10074015-L-assistenza-e-l-intervento-educativo-alla-persona-portatrice-di-cannula-tracheale.html
3	NHS – Southern Health – NHS Foundation Trust – SH CP 214 <u>Author:</u> Guy S.	Tracheostomy Care Guidelines	Guideline	October 2017 https://www.southernhealth.nhs.uk/resources/assets/attachment/full/0/153927.pdf
4	West Suffolk – NHS Foundation Trust <u>Document owner:</u> Lewis S., Ingalla G.	Tracheostomy/ Laryngectomy: Managing the Patient	Trust Policy and Procedure Document Reference: PP(17) 315 Guideline	August 2017 https://www.wsh.nhs.uk/CMS-Documents/Trust-policies/301-350/PP(16)315TracheostomyLaryngectomyManagingthePatient.pdf
5	NSW – Health - Nepean Blue Mountains Local Health District <u>Author:</u> Carpen H.	Care of Adult Patients with a Tracheostomy Tube	Procedure	January 2015 http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0008/292580/Tracheostomy-care-nbm.pdf
6	NHS – QE Gateshead – Quality and excellence in health <u>Authors/Reviewer</u> Wood M. & Marr H.	Management of adult patients with a tracheostomy or laryngectomy	Policy No OP80	February 2017 https://www.qegateshead.nhs.uk/sites/default/files/users/user10/OP80%20Management%20of%20Adult%20Patients%20with%20a%20Tracheostomy%20or%20Laryngectomy%20v2.pdf

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Table 1 (continued). Records selected related to Tracheostomy management

7	Regione Lombardia –ASST Pavia <u>Working group:</u> Bassi S., Corsi P., Di Martino B., Galloni D., Lazzati R., Mirabile P., Noto C., Zampieri G. <u>Collaborators</u> Castigliola L., Filippone M., Lanza L., Martinotti R., Targa M.	Gestione cannule tracheali e l'educazione al paziente [Tracheal tube management and the patient education]	Operational protocol	January 2016 https://docplayer.it/44173796-L-educuzione-al-paziente.html
8	St James's Hospital Nursing, <u>Owner:</u> Ms Norton J. Tracheostomy Care Working Group <u>Reviewed by:</u> Prof. Timon C., Mr Kinsella J., Prof. Stassen L., Dr. Fagan C., Dr. Moriarty J., Ms. Roche M., Ms. Brady A. <u>Approved by:</u> Mr Gallagher P.	Tracheostomy Care Guidelines	Guidelines	December 2013 http://www.stjames.ie/GPsHealthcareProfessionals/ConferencesCourses/TracheostomyTalks/Tracheostomy%20Guidelines%20(2013).pdf
9	St George's Healthcare NHS Trust Brunker C., Dawson D., Dr Kourteli E., Maistry N., More M., Wilkinson O., Kelly G.	Guideline for the Care of Patients with Tracheostomy Tubes	Guideline	2012 Edition http://replantmed.hu/tudaskozpont-replantmed/category/6-intenziv-terapia-es-anesztezia?download=24:guidleline-traceosztomias-betegeknek
10	Tracheostomy Care – Intensive care Society Standards <u>Prepared on behalf of the Council of the Intensive Care Society by:</u> Bodenham A. (Chair), Bell D., Bonner S., Branch F., Dawson D., Morgan P., McGrath B., Mackenzie S.	Standards for the care of adult patients with a temporary Tracheostomy; STANDARDS AND GUIDELINES	Guideline	2014 https://www.theawesomecourse.co.uk/ICS/ICS%20Tracheostomy%20standards%20(2014).pdf

to assist patients with tracheostomies. One evaluated the patient upon his/her arrival in the hospital with a check list for the procedures and evaluations to be carried out. Five forms recorded the evaluation of the patient's condition and/or the presence of apparatus. And one was a check list of the material and equipment that were available to the patient upon release from the hospital. But we did not analyzed them as they were not on topic with regards to our project.

An operational protocol was created called "*Assistance and Therapeutic Education for the Laryngectomized or Tracheotomized Patient Belonging to the Diagnostic-Therapeutic-Assistance Path for the Oncologic Head Neck Disease.*". Its goal was to line up nursing skills with recent scientific evidence – while also standardizing behavior inside the group – and to set up a standard educational plan customized for each patient/caregiver to promote his/her self-care.

The document was divided into two parts. It also had two attachments which were equivalent to self-standing documents:

- **PART I** – A detailed description was given for all the procedures that nurses carry out – completely on their own, or in the presence of an otolaryngologist – related to the handling of a medium-term tracheotomy or a tracheostomy, tracheal tube, along with any other apparatuses, devices, or dispositions designed to guarantee the airway patency and prevent the onset of complications. The second part of the operational protocol is based on this.

- **PART II** – After the concept of therapeutic education and self-care was introduced, a description of the methodology regarding both the patient and the caregiver was presented. Next, the subjects were

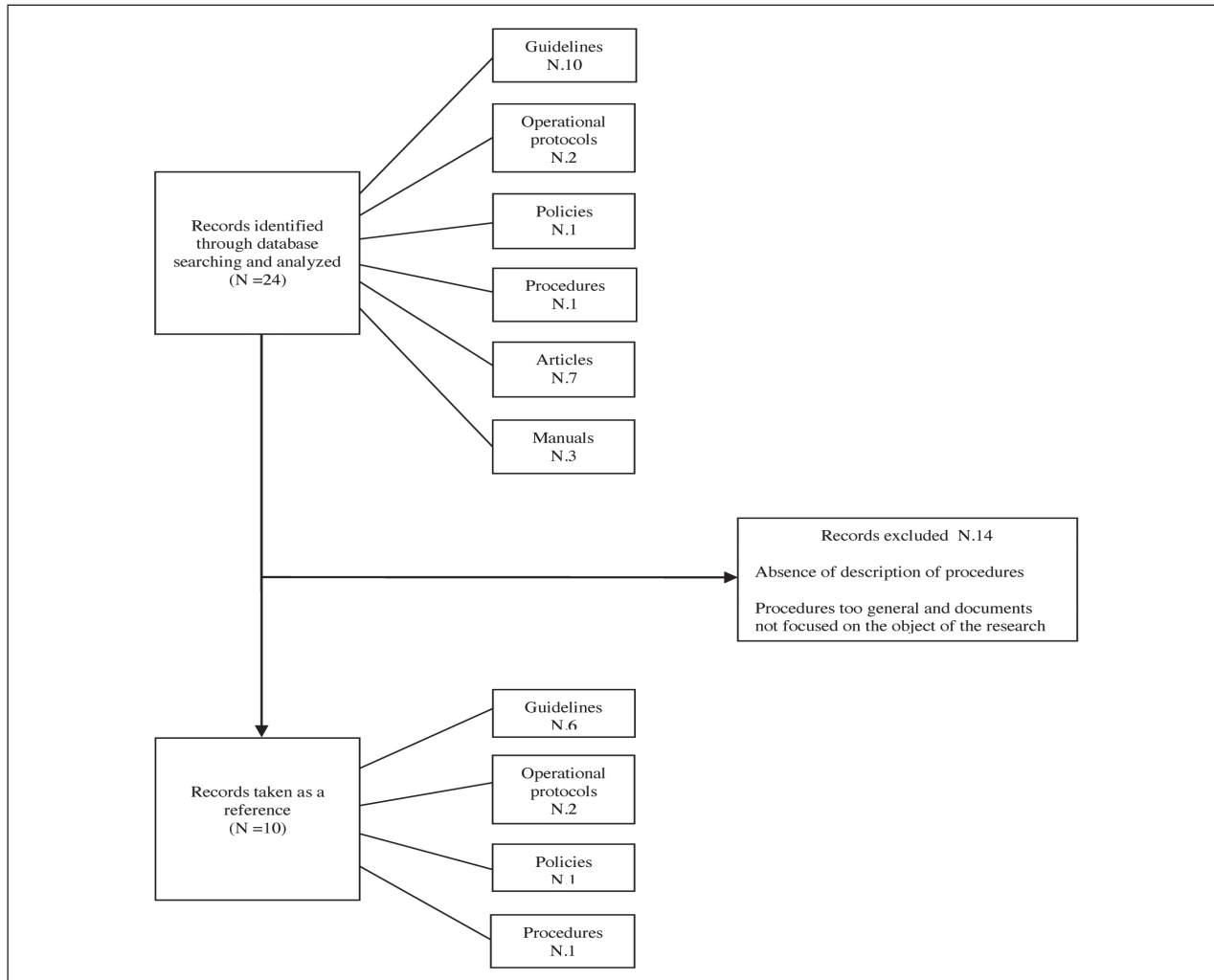


Figure 1. Tracheostomy management literature review flow diagram

described in detail: the specific goals, contents, methods, roles, instruments employed, and the modes used to evaluate the patient’s understanding. A distinction was made between the patient who has undergone a total laryngectomy and the patient with a temporary tracheotomy, as some of the procedures can be done autonomously in the former case, but not in the latter.

Evaluation of the patient’s learning is a rather difficult process. It is necessary to use validated and objective methods and instruments that are addressed to the patient and/or the caregiver. The former is totally or partially unable to express himself/herself in words during the days that followed the surgery. And so, we decided to verify the patient’s understanding of our ex-

planation of procedure techniques by simply observing the patient/caregiver, using the procedures summarized in this part of the protocol. But the evaluation of the patient’s ability to handle this new condition – and namely the level of self-care reached – is much more complex, and therefore a more appropriate instrument should be used in the future. (12)

• **ATTACHMENT I – “Form used to record tracheostomized patient education”**

We created a form which records training given to patients and/or caregivers. It is intended to highlight and record the subjects explained, along with the extent to which they are able to understand what is

Table 2. Records selected about Therapeutic Education and Self-Care

N.	Authors	Title	Record	Source and Date
1	Bagnasco A., Calza S., Petralia P., Aleo G., Fornoni L., Sasso L.	Investigating the use of Barrows Cards to improve self-management and reduce healthcare costs in adolescents with blood cancer: a pilot study	Article	J Adv Nurs. 2016 Apr; 72(4):754-8.
2	Beghelli A., Ferraresi A., Manfredini M.	Educazione terapeutica. Metodologia e applicazioni [Therapeutic Education. Methodology and applications]	Book	Carocci Faber 2015
3	Bickford J.M., Coveney J., Baker J., Hersh D.	Support following total laryngectomy: Exploring the concept from different perspectives	Article	Eur J Cancer Care (Engl) 2018 May; 27(3):e12848.
4	Bobbo N.	Fondamenti pedagogici di educazione del paziente [Pedagogical foundations of education to the patient]	Book	CLEUP Editore 2012
5	Bowers B., Scase C.	Tracheostomy: facilitating successful discharge from hospital to home	Article	Br J Nurs 2007 Apr 26-May 9;16(8):476-9
6	Prof. Brook I., Italian translation by Dr. D'Ascanio L., Dr. Ori M.	La Guida per il Paziente Laringectomizzato [The Laryngectomee Guide]	Book	November 2017 www.aooi.it/wp-content/uploads/2017/11/Guida-al-Paziente-Laringectomizzato.pdf
7	Cnossen I.C., van Uden-Kraan C.F., Eerenstein S.E., Rinkel R.N., Aalders I.J., van den Berg K., de Goede C.J., van Stijgeren A.J., Cruijff-Bijl Y., de Bree R., Leemans C.R., Verdonck-de Leeuw I.M.	A Participatory Design Approach to Develop a Web-Based Self-Care Program Supporting Early Rehabilitation among Patients after Total Laryngectomy	Article	Folia Phoniatr Logop 2015; 67(4):193-201
8	General Direction S.I.T.R.A., Regione Lombardia, ASL Brescia. <u>Manager:</u> Dr. Di Meo S. SITRA ASL Brescia. <u>Working groups coordinator:</u> Crescini L. - SITRA - ASL Brescia <u>Working group:</u> Agazzi C., Baruffaldi S., Bertozzi E., Bianchetti S., Di Benedetto F., Fappani M., Fiorini J., Luvriti C., Franzini M. A., Guarneri S., Menchi V., Pollini S., Roberti O., Shaban Y., Venturi A., Festa G., Foglia V., Gaia M., Leali R., Raccagni M., Romagnoli P., Sbaraini C., Beruffi M. S.	L'assistenza e l'intervento educativo alla persona portatrice di cannula tracheale [Assistance and training for the patient with a tracheal tube]	Operational Protocol	December 2011 https://docplayer.it/10074015-L-assistenza-e-l-intervento-educativo-alla-persona-portatrice-di-cannula-tracheale.html

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Table 2 (continued). Records selected about Therapeutic Education and Self-Care

9	Jaarsma T., Cameron J., Riegel B., Strömberg A.	Factors Related to Self-Care in Heart Failure Patients According to the Middle-Range Theory of Self-care of Chronic Illness: a Literature Update	Article	Curr Heart Fail Rep. 2017 Apr; 14 (2):71-77
10	McDonald J., McKinlay E., Keeling S., Levack W.	Becoming an expert carer: the process of family carers learning to manage technical health procedures at home	Article	J Adv Nurs. 2016 Sep;72(9):2173-84
11	Mehta A.B., Wiener R.S., Reardon C.C.	Living with a Tracheostomy	Article	Am J Respir Crit Care Med. 2016 Aug 1;194(3):P5-6
12	World Health Organization – Office for Europe Copenhagen Report of a WHO Working Group	Educazione terapeutica del paziente [Therapeutic education of the patient]	Training program for educators	1998- Italian translation March 2007 www.assdiabre.it/files/Raccomandazione-OMS-su-Educazione-Terapeutica-.pdf
13	Regione Lombardia – ASST Pavia Working group: Bassi S., Corsi P., Di Martino B., Galloni D., Lazzati R., Mirabile P., Noto C., Zampieri G. Collaborators Castigliola L., Filippone M., Lanza L., Martinotti R., Targa M.	Gestione Cannule Tracheali e l’educazione al paziente [Tracheal tube management and the patient education]	Operational protocol	January 2016 https://docplayer.it/44173796-L-educazione-al-paziente.html
14	Riegel B., Jaarsma T., Strömberg A.	A Middle-Range Theory Of Self-Care Of Chronic Illness	Article	ANS Adv Nurs Sci. 2012 Jul-Sep; 35(3): 194-204
15	Singer S., Danker H., Guntinas-Lichius O., Oeken J., Pabst F., Schock J., Vogel H.J., Meister E.F., Wulke C., Dietz A.	Quality of life before and after total laryngectomy: results of a multicenter prospective cohort study	Article	Head Neck. 2014 Mar;36(3):359-68
16	St George’s Healthcare NHS Trust Bruncker C., Dawson D., Dr Kourтели E., Maistry N., More M., Wilkinson O., Kelly G..	Guideline for the Care of Patients with Tracheostomy Tubes	Guideline	2012 Edition http://replantmed.hu/tudaskozpont-replantmed/category/6-intenziv-terapia-es-anesztezia?download=24:guideine-trachosztomias-betegeknek
17	Woisard V., Galtier A., Baumann L., Delpierre C., Puech M., Balaguer M.	Therapeutic education of total laryngectomy patients: Influence of social factors	Article	Rev Laryngol Otol Rhinol (Bord). 2015;136(5):171-9
18	Wong K., Gilad A., Cohen M.B., Kirke D.N., Jalisi S.M.	Patient education materials assessment tool for laryngectomy health information	Article	Head Neck. 2017 Nov;39(11):2256-2263

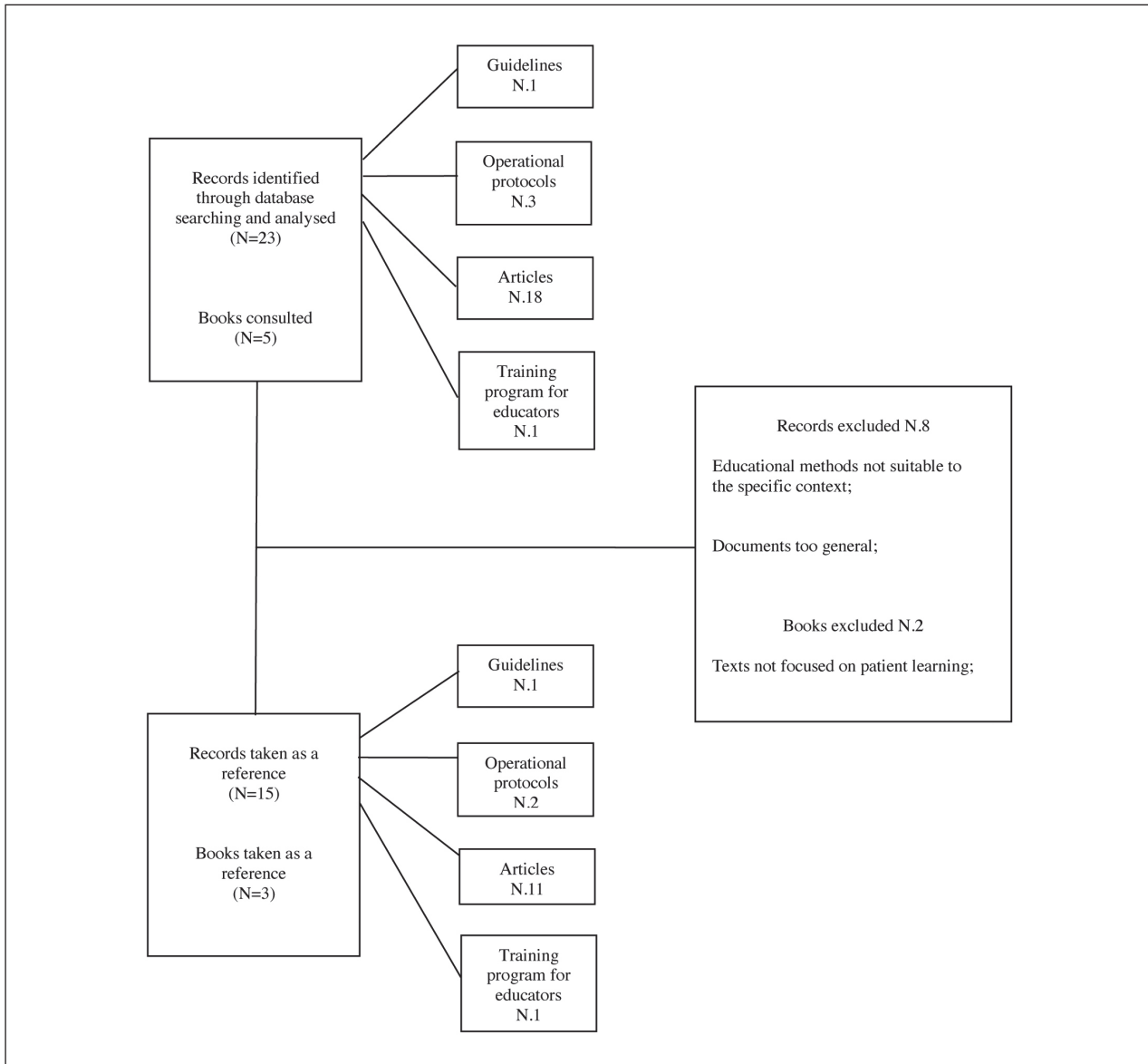


Figure 2. Therapeutic education and Self-Care literature review flow diagram

proposed to them. We used as a reference one of the two forms that we had found during our bibliographical research, because it conformed with our needs and our context (13).

The top of the form provides space for the user's personal data (that of the patient or the caregiver). Next comes the identification of the subjects dealt with by the nurses. For each of these, the date of the training session is to be submitted, along with the name of the operator responsible for it, data regarding the extent of

the patient's learning and comprehension, and if the set goal has been achieved or not.

Given the importance of customizing the training plan and the need to give the patient and/or caregiver time to assimilate the information provided and the procedures explained, several observations could be recorded on the same subject. Space is not included for observations related to speech therapists and dietitians, as these are to be recorded in a counseling report.

• **ATTACHMENT II** – Booklet entitled, “*Useful information for a person undergoing a total laryngectomy*”.

This document is to be given to the patient or caregiver at the start of his/her education. It reinforces the training and acts as a useful reference upon the patient’s return home. It supplies general and procedural information, but also helps the patient and family members become familiar with care and assistance upon discharge. Subjects dealt with during this educational phase is summarized in a booklet designed for consultation when in need. The subjects are as follows:

1. Anatomy and physiology of the upper aero and digestive tract.
2. Total laryngectomy
3. Tracheal tube and accessories
4. The humidification, filtration, and heating of the respiratory mucous membrane
5. The rules of hygiene and the awareness of other factors
6. The suction of the endotracheal secretions
7. The substitution and cleaning of the inner tracheal tube (if present)
8. Substitution of the tracheostomy tube
9. Care of the tracheal stoma
10. Recovering the ability to speak
11. Cleaning of the vocal prosthesis (if present)
12. Alimentation
13. Treatments after discharge from the hospital
14. Physiotherapy
15. Protected discharge
16. How to reach us by phone

Once the documentation produced and approved by both the Chair of the Operational Unit and by the Director of the Health Professions Operational Unit, we proceeded to make it official on the hospital website and moved on to the implementation of the educational program that we had created.

These last stages also concluded the related training project. The documents produced and the final results were sent to the Simple Departmental Structure for Training and Communication. This led to Continuing Medical Education accreditation, along with recognition given to all the participants.

Conclusion

This project combined training, research, and organization with assistance for the patient. It provides food for thought as a starting point for improving normal procedures. By procedures we mean both the handling of tracheotomies-tracheostomies and the implementation of therapeutic education for the patient/caregiver.

This subject demands the confirmation that one can and should change one’s own behavior. “Workplace-based Learning” can provide this. Through this methodology the nurses of the “Improvement group” have increase their knowledge of subjects of daily interest, aligning their skills. Moreover it gave them the opportunity to take part in a training exercise that was organized “ad hoc” with the additional intention of minimizing personal discomfort, while still guaranteeing preset objectives within set times.

Only too often nurses who wished to participate in training courses related to their specialty, found it difficult to attend these courses – due to family reasons and personal inhibitions deriving from the need to respect the rules inherent in work schedules.

Even the other specialists showed themselves to be favorable and available to undertake this route of improvement. Their involvement also encouraged the integration of the multidisciplinary and multi-professional team, creating yet more added value and giving birth to valuable collaborations.

Surely this project has shown one of the many contributions that the nurse can make during the patient’s pathway. The nurse’s work thereby becomes more visible. This is a starting point which should lead to active participation in Disease Management Team activities, also through the establishment of a Case/Care Manager.

Discussion

This project stimulated reflection on some themes and proposals such as:

- Adding at least one indicator of the nursing process to the budget
- Organizing training courses for all those who carry out therapeutic educational activities in

their own work contexts to help them acquire adequate skills

- Organizing Continuing Medical Education accredited seminars for external health operators, with the goal of optimizing the handling of this type of patient in a home environment, and also encouraging integration with the hospital
- Instituting an outpatient nursing clinic dedicated to continuing therapeutic education after the patient's discharge from the hospital, monitoring his/her learning until the patient/caregiver is completely autonomous
- Formally setting up a group of nurses who can provide their colleagues in other operational units with advice regarding tracheostomy patients, upon request
- A better research for the appropriate instruments to evaluate patient self-care

In a health context which deals, to an ever increasing degree, with chronic illness, it is essential to be able to face patients' various needs for assistance. It becomes ever more important to be able to recognize and evaluate the contribution of each single professional, the skills that they have, and their personal ability to develop and apply them.

To do so, action must be taken through training, organization able to support the various processes, and professionals to motivate them and bring out their value, are all necessary. Conditions must also be created to help them to work to their best, guaranteeing positive results for the users (4, 14, 15).

For some time now, researchers have been occupied with outcomes, evaluating the effect of nursing activities on patients. Successes have been identified that relate directly to this. They focus on all the tools which allow them to be measured and monitored, and on all the factors which influence their creation (8, 14, 15).

In addition, scientific literature shows that quality assistance is reached in settings in which there is a high degree of satisfaction both on the part of the patient, as on the part of the doctors and nurses (14, 15).

Nurses have a greater impact when they are given charge of the patient. They need to feel they have more autonomy and control over practices; that they can influence decisions, participate in the logic behind them

and the handling of priorities, even while fully participating in organizational choices. Coordinators and managers at various levels need to take action to make this occur. And the training project we have initiated intends to work precisely on all these aspects.

We set the promotion of Self-Care as our overall goal, as the main palpable outcome of nursing a patient afflicted by a chronic illness. We managed to act on both the quality of assistance given to the patients with medium-term tracheotomy or laryngectomy and on the skills of the nurses involved, along with their motivation and multidisciplinary and multi-professional integration on the Disease Management Team.

"Workplace-based Learning" methodology has surely shown itself as added value. It has indirectly allowed for the achievement of organizational-related goals in addition to ones regarding training. And so, to continue to improve quality, it is not just a point of arrival, but also a point of departure towards a further implementation of the culture of taking charge of a patient. We feel that the real difficulty was not in the making of this project, in spite of its complexity, but will be in the guaranteeing of the constant application of the operational protocol which we have created. Many different critical points are present in the organizational context. They must be taken into consideration in order to produce real change. This study should not remain a work unto itself.

Furthermore, though training shows its efficiency by enabling learning, seen as a process which leads to a change in the learner's way of thinking, feeling, and acting (16), we feel that it is important to identify an appropriate mode for evaluating the skills that have been acquired by health operators at the end of this path. The impact of the quality of assistance given also strongly impacts outcome.

Limits

- The modes used to evaluate how the patient or caregiver learns to deal with a new psycho-physical condition after surgery could be improved by using more appropriate tools.
- The large size of the work group created the need for a great deal of time and coordination.

- Five of the nurses (20%) for personal reasons were not able to finish the training process.
- The bibliographic searches carried out were not systematic reviews of the literature.

Conflict of interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article

References

1. Ministero della Salute. Direzione Generale della programmazione sanitaria. Piano Nazionale della Cronicità. Accordo tra lo Stato, le Regioni e le Province Autonome di Trento e di Bolzano del 15 settembre 2016 [National Plan for Chronic Illnesses. Agreement between the State, the Regions, and the Autonomous Province of Trento and Bolzano, dated September 15, 2016].
2. Cavaliere B., Manzoni E., Piu F. Innovazione e Governance delle Professioni Sanitarie. Scenari di sviluppo per una sanità a misura d'uomo. [Innovation and Governance of Health Professions. Development scenarios for human health]. Casa Editrice Ambrosiana, 2015.
3. Servizio Sanitario Regionale Emilia-Romagna, Azienda Ospedaliera di Reggio Emilia. Arcispedale S. Maria Nuova, Direzione Professioni Sanitarie – D.P.S., Dott.ssa Marina Iemmi Direttore. Il modello per intensità di cura e complessità assistenziale: il punto di vista della DPS [The model for intensity and complexity of care: the point of view of the Directorate of Health Profession]. Emissione 21 Maggio 2012.
4. A cura di Orlandi C., Calamandrei C.. Manuale di management per le professioni sanitarie [Health Professionals Management Manual], McGraw-Hill Education, 2015.
5. Chiari P., Santullo A.. L'infermiere case manager dalla teoria alla prassi. [The Nurse as the Case Manager: from theory to practices] Mc Graw Hill, Milano, 2011.
6. Beers E., Lee Nilsen M., Johnson J.T.. The Role of Patients: Shared Decision-Making. *Otolaryngol Clin North Am.* 2017 Aug;50(4):689-708.
7. World Health Organization Regional Office for Europe Copenhagen. Therapeutic Patient Education – Continuing Education Programmes for Health Care Providers in the Field of Prevention of Chronic Disease. Report of a Who Working Group, 1998. EUR/ICP/QCPH 01 01 03 Rev. 2 Original: English.
8. Doran D. M.. Nursing outcomes – gli esiti sensibili alle cure infermieristiche [Nursing outcomes]. Mc GrawHill Education, 2013.
9. Riegel B., Jaarsma T., Strömberg A.. A middle-range theory of self-care of chronic illness. *ANS Adv Nurs Sci* . 2012 Jul-Sep; 35 (3):194-204.
10. Marzano A., Parisi G.. Organizzare la formazione sul campo. Metodi, modelli ed esperienze [Organizing Training in the Field: Methods, models, and experiences]. *Tutor. Vol.17, N..3, 2017:21-28.*
11. AGENAS. FSC e criteri per l'assegnazione dei crediti ECM alle attività di FSC [Workplace-based learning and the criteria for the assignment of CME credit to workplace-based learning activities]. In: http://ape.agenas.it/documenti/3_Formazione_sul_campo.pdf.
12. Bagnasco A., Calza S., Petralia P., Aleo G., Fornoni L., Sasso L.. Investigating the use of Barrows Cards to improve self-management and reduce healthcare costs in adolescents with blood cancer: a pilot study. *J Adv Nurs.* 2016 Apr;72(4):754-8.
13. Direzione Generale S.I.T.R.A, Regione Lombardia, Asl Brescia. L'assistenza e l'intervento educativo alla persona portatrice di cannula tracheale [Assistance and training for the patient with a tracheal tube] Dicembre 2011, Rev.00.
14. Aiken L.H., Clarke S.P., Sloane D.M., Lake E.T., Cheney T.. Effects of hospital care environment on patient mortality and nurse outcomes. *J Nurs Adm.* 2008 May;38(5):223-9.
15. Aiken L.H., Sermeus W., Van den Heede K., Sloane D. M., Busse R., McKee M., Bruyneel L., Rafferty A.M., Griffiths P., Moreno-Casbas M.T. Tishelman C., Scott A., Brzostek T., Kinnunen J., Schwendimann R., Heinen M., Zikos D., Sjetne I.S., Smith H.L., Kutney-Lee A.. Patient safety, satisfaction, and quality of hospital care: cross sectional surveys of nurses and patients in 12 countries in Europe and the United States. *BMJ* 2012;344:e1717.
16. Gilbert J.J.. Guida Pedagogica per il personale sanitario. [Teaching Guide for health personnel]. Edizioni Dal Sud, 2002.
17. Woisard V., Galtier A., Baumann L., Delpierre C., Puech M., Balaguer M.. L'éducation thérapeutique du patient laryngectomisé total: influence des facteurs sociaux. [Therapeutic education of total laryngectomy patients: Influence of social factors]. *Rev. Laryngol. Otol. Rhinol. (Bord).* 2015;136(5):171-179.
18. Wong K., Gilad A., Cohen M.B., Kirke D.N., Jalisi S.M.. Patient education materials assessment tool for laryngectomy health information. *Head Neck.* 2017 Nov;39(11):2256-2263.
19. Pérol D., Toutenu P., Lefranc A., Régnier V., Chvetzoff G., Saltel P., Chauvin F.. L'éducation thérapeutique en cancérologie: vers une reconnaissance des compétences du patient. [Therapeutic education in oncology: involving patient in the management of cancer]. *Bull Cancer* 2007;94(3):267-74.
20. Buiet G., Chidiac F., Pujo K., Combe C.. Comment concilier éducation thérapeutique des patients et parcours de soin en cancérologie: application pour le voies aérodigestives supérieures. [How to reconcile therapeutic patient education and care pathology in oncology: Application in head and neck neoplasm]. *Bull Cancer* 2019;106:468-478.
21. McDonough K., Crimlisk J., Nicholas P., Cabral H., Quinn EK., Jalisi S. Standardizing nurse training strategies to improve knowledge and self-efficacy with tracheostomy and laryngectomy care. *Appl Nurs Res.* 2016 Nov;32:212-216.

22. Singer S., Danker H., Guntinas-Lichius O., Oeken J., Pabst F., Schock J., Vogel H.J., Meister E.F., Wulke C., Dietz A.. Quality of life before and after total laryngectomy: Results of a multicenter prospective cohort study. *Head Neck*. 2014 Mar;36(3):359-68.
23. Pereira da Silva A., Feliciano T., Vaz Freitas S., Esteves S., Almeida E Sousa C., Quality of life in patients submitted to total laryngectomy. *J Voice*. 2015 May;29(3):382-8.
24. McDonald J., McKinlay E., Keeling S., Levack W.. Becoming an expert carer: the process of family carers learning to manage technical health procedures at home. *J Adv Nurs*. 2016 Sep;72(9):2173-84.
25. Cnossen I.C. van Uden-Kraan C.F., Eerenstein S.E.J., Rinkel R.N.P.M., Aalders I.J., van den Berg K., de Goede C.J., van Stijgeren A.J., Cruijff-Bijl Y., de Bree R., Leemans C.R., Verdonck-de Leeuw I.M.. A Participatory Design Approach to Develop a Web-Based Self-Care Program Supporting Early Rehabilitation among Patients after Total Laryngectomy. *Folia Phoniatri Logop*. 2015;67(4):193-201.
26. Beghelli A., Ferraresi A., Manfredini M.. Educazione terapeutica. Metodologia e applicazioni. [Therapeutic Education..Methodology and applications]. Carocci Edizioni, 2015.
27. Bobo N., Fondamenti pedagogici di educazione al paziente. [Pedagogical foundations of education to the patient]. CLEUP editore, 2012.
28. Kolb D.A.. *Experiential learning*. Englewood Cliffs, N.J.: Prentice Hall, 1984.
29. Copanitsanou P., Fotos N., Brokalaki H.. Effects of work environment on patient and nurse outcomes. *Br J Nurs*. 2017 Feb 9;26(3):172-176.
30. Choi J., Boyle D.K.. Differences in nursing practice environment among US acute care unit types: a descriptive study. *Inf J Nurs Stud*. 2014 Nov;51(11):1441-9.

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FORM USED TO RECORD TRACHEOSTOMIZED PATIENT EDUCATION

PATIENT <input type="checkbox"/> SURNAME _____ NAME _____ DATE OF BIRTH _____ TEL _____	CAREGIVER <input type="checkbox"/> SURNAME _____ NAME _____ DATE OF BIRTH _____ TEL _____
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<u>1° TOPIC</u>	<i>DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL</i>														<i>NOTES</i>						
Anatomy and physiology of the respiratory system																					
<u>1° OBJECTIVE</u>	<i>DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL</i>																				
The patient/caregiver knows the organs of the respiratory system and their function																					
GOAL ACHIEVED																					
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	
<u>2° TOPIC</u>	<i>DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL</i>														<i>NOTES</i>						
Tracheotomy, tracheostomy and tracheal tube																					
<u>2° OBJECTIVE</u>	<i>DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL</i>																				
The patient/caregiver knows the distinction between tracheotomy and tracheostomy, and the main features of the tracheal tube he has been supplied																					
GOAL ACHIEVED																					
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	

3° TOPIC	DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL																		NOTES		
Hygiene rules and other precautions																					
3° OBJECTIVE	DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL																				
The patient/caregiver knows the hygiene rules and the precautions to be taken daily																					
	GOAL ACHIEVED																				
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	
4° TOPIC	DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL																		NOTES		
Replacement and cleaning of the inner tracheal tube																					
4° OBJECTIVE	DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL																				
The patient/caregiver will be able to independently replace and clean the inner tracheal tube																					
	GOAL ACHIEVED																				
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	
5° TOPIC	DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL																		NOTES		
Suctioning of endotracheal secretions																					
5° OBJECTIVE	DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL																				
The patient/caregiver will be able to independently perform the procedure of endotracheal secretion suctioning																					
	GOAL ACHIEVED																				
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	

6° TOPIC	DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL																		NOTES	
Replacement of the tracheostomy tube																				
6° OBJECTIVE	DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL																			
The patient/caregiver will be able to independently perform the procedure of replacement of the tracheostomy tube	GOAL ACHIEVED																			
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	
7° TOPIC	DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL																		NOTES	
Stoma care																				
7° OBJECTIVE	DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL																			
The patient/caregiver will be able to independently perform the clening of the stoma	GOAL ACHIEVED																			
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	
8° TOPIC	DATE OF THE EDUCATIONAL INTERVENTION AND INITIALS OF THE HEALTH PROFESSIONAL																		NOTES	
Respiratory hygiene																				
8° OBJECTIVE	DATE OF THE EVALUATION AND INITIALS OF THE HEALTH PROFESSIONAL																			
The patient/caregiver, will be able to promote the humidification, filtration and heating of the respiratory mucosa	GOAL ACHIEVED																			
	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	NO	YES	