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ORIGINAL ARTICLE

Developing an integrated care pathway to connect home-based palliative care and emergency departments: participatory action research on a quality improvement project

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Abstract. This study presents a participatory action-research framework aimed at improving the integration of palliative care (PC) in emergency departments (ED). The research describes the development and implementation of a clinical pathway for PC patients accessing emergency services in Modena, Italy. Through a mixed-methods approach, including interviews, questionnaires, and observational data, the study outlines the participatory process, the resulting clinical pathway, and baseline measures. Key findings include active engagement of healthcare professionals in pathway development, successful training initiatives, and the establishment of a structured approach to PC in the ED. The study emphasizes the importance of participatory approaches in addressing complex healthcare challenges and highlights the need for ongoing evaluation of integrated PC models in emergency settings. (www.actabiomedica.it)

Key words: palliative care, emergency department, integrated care pathway, participatory action research

Introduction

Palliative Care (PC) should be accessible to everyone (1). With the increasing aging population and the burden of non-communicable diseases, a growing number of patients access the emergency room (ER) several times in the last year of life (2,3). To date, palliative care target patients in need of emergency care often do not find a setting that is able to provide a fully appropriate care plan for them (4). In Italy, unlike other countries, PC are not linked to the services provided by the Emergency Department (ED). Thus, many needs of the frailest population are underestimated or unmet. Both emergency practitioners and the PC community have increasingly recognized the need to provide PC in ED (5-7), reflecting the rising attitude towards a wider change in chronic disease care attitudes. The development of bidirectional targeted pathways is crucial to ensure palliative care candidates' referral when accessing the ED and the provision of proportionate emergency interventions to community PC patients (2,6,8). This should have a positive impact on inappropriate admissions and treatments (3,9). Preliminary data indicate that a palliative care consultation performed in an emergency department can reduce hospital stays and decrease daily costs (10).

Training ED professionals to provide palliative care

Providing adequate training to emergency professionals is pivotal to ensure consistent palliative care in the emergency department (10,11). Studies have shown that emergency physicians who received end-of-life (EOL) care training felt more comfortable providing such care and discussing it with both patients and their families. Physicians reported training needs in the management of physical disorders, communication skills, and the ethics of EOL care. What is more, professionals receiving EOL training were more aware of the value of communication skills than just managing symptoms (12). Among different models of training delivery, a peer-based approach to teaching palliative care helped emergency physicians get more experienced (11).

Current integrated palliative care models

Worldwide literature has flourished to solve the problem of inadequate provision of palliative care in the EDs since 2008, when the American Board of Emergency Medicine became the official sponsor of Palliative Medicine and Hospice as a subspecialty (11). Different strategies have been adopted according to three main recurrent models, used one at a time or in combination: 1) ED-PC partnership, 2) ED-PC champions, 3) and ED-hospice partnership (13). In fact, some hospitals use an integrated care model in which ED providers perform primary PC interventions with each patient. Others have a consultative model with a multidisciplinary PC team outside the hospital… A program with two nurses trained to early identification of PC eligible patients allowed more discharges from the ED to hospice, avoiding hospitalization (11). in an Ohio study, using ED-specific tools and ER visits resulted in higher admissions to PC from the ED (10). In another study, an adapted version of the ED Screening for Palliative and End-of-Life Care Needs (5-Speed), helped ED professionals in recognizing the unmet PC needs for 40 percent of cancer patients (6). Even other positive results on outcomes like average hospital stay time, daily cost of care and length of stay were obtained with similar models (10).

No "one size fits all" solutions

The evidence highlights no "one size fits all" answer to the issue of integrating palliative care in emergency settings (14). How can we choose between the available models and implement a customized change in such a complex, inter-institutional, and inter-professional system? A participative paradigm, as described in this paper, might be a way of developing sustainable and tailored solutions for palliative care implementation (15).

This study aims were:

- to create a clinical pathway for improving organizational outcomes in patients with palliative care needs who use emergency services, using an action-research framework ("planning, acting, observing, and reflecting");
- to describe the "T0" context in which the clinical pathway is going to be implemented, in terms of knowledge, reception and perceptions of ED and PC health professionals, regarding in particular of possible context-specific problems and obstacles in the implementation of such a project.

Patients and methods

This is a participatory action-research using mixed methods, resulting in a quality improvement project. Participatory action-research is a mainly qualitative methodology derived from the social sciences that aims to produce knowledge in a context while you are trying to modify it (16). Palliative care interventions often require a cultural change, and this methodology allows the researchers to describe the participatory dynamics involved in a social process. We considered the "participatory paradigm" as our theoretical paradigm of reference, acknowledging it as an independent paradigm suitable for these types of interventions (17). It is a 'professionalizing type' action research according to the classification of Hart et al (18), where the goals of the intervention and their achievement are set by the professionals themselves, and that the purpose of intervention is to solve problems in a specific work environment. This report is drawn according to the current SQUIRE guidelines for quality improvement project (19). We also took in account the best practices in the reporting of participatory action research (20), checking that all the suggested in the guideline aspects were considered.

Context – Description of Local Palliative Care Network

The project took place in the province of Modena, Italy. In the Italian Healthcare System, the creation of a formal Regional and Local Palliative Care Network is recommended by law. In our specific context, the PC Network is a branch of the Department of Primary Care, has a single coordinator, and consists of different hubs: hospital consulting, community care, outpatient services, and hospice. The Emergency Rooms (ER), ambulance services, and operations center are all gathered in the Emergency Department (ED). This specific intervention aimed at improving communication and organizational outcomes between the community care hub and the different sections of the ED.

Intervention(s)

A participatory, interdisciplinary, and interinstitutional group of 20 health professionals, including physicians and nurses from primary care, emergency, and palliative care departments, collaborated for a year and a half to draft a shared clinical emergency pathway for palliative care patients. This initiative aimed to enhance outcomes, assess care needs, and provide related training for professionals by creating a structured pathway for palliative care patients. We described the participative process in greater detail in Table S1 1. In the group implemented a bi-component intervention comprising educational and organizational elements.

The educational intervention included a two-module training program. The first module involved asynchronous online training, where participants reviewed a 30-minute video explaining the official document and completed a multiple-choice questionnaire. This was followed by a mandatory 4-hour in-person session to discuss the new official document approved by the local health authority. All training sessions used examples and video demonstrations in settings and with professionals familiar to the target professionals, thanks to the interprofessional team that built them.

The organizational intervention led to the development and approval of a new clinical pathway, now part of the local health authority's procedures. The pathway details the actions expected from professionals in two scenarios: patients with palliative care needs identified during an emergency department visit and patients already receiving home-based palliative care. For the former, emergency department staff would treat and discharge patients with a module to notify the out-of-hospital palliative care service, initiating further assessment and care. For the latter, specific needs and dispositions, such as choosing palliative sedation over intubation for ALS patients during respiratory failure, would be communicated to emergency services via a "warning procedure," ensuring appropriate palliative care is provided in line with the patient's wishes.

Study of the intervention(s)

We describe the participatory project through qualitative and quantitative measures. We interviewed a sample of 11 members of the working group at T0, before the implementation of the clinical pathway, to gain a deeper comprehension of the participative process. We also proposed an anonymous questionnaire to the whole emergency department's staff at T0, to have a better understanding of the environment in which we implemented the project and for future comparisons. We planned further administrations of the interview and the questionnaire at T1 (six months from the starting of the implementation) for future comparison and to generate hypothesis on the effects of the intervention.

Data analysis

Qualitative analysis: we performed thematic analysis of the interviews. Two researchers (LR and FR) independently generated codes, analyzing the semantic level of the data and using mainly an inductive method, leading to the definition of themes and subthemes. Each one separately built a theme map, and a third researcher (GM) supervised the construction of a common, shared map and list of themes. A more detailed description of themes, their inclusion and exclusion criteria and verbatim is in Table S2. We increased the trustworthiness of our data addressing their credibility, dependability, and confirmability through "triangulation of data sources", triangulation of researchers", "consensus among different coders", member checking (with three members of the working group) and reflexivity (see the "limitation" section), as suggested by Luciani and Campbell (21). Two authors (CC and LR) took part in meetings and training events as non-participant observers and produced field notes, used to triangulate the qualitative analysis.

Quantitative analysis: the questionnaires are described in terms of absolute numbers and percentages of respondents. Participatory action research is qualitative in nature, but quantitative data can be used to triangulate and help interpret the qualitative findings. The questionnaires were analyzed using the software Microsoft Excel®.

Measures

Three main measuring dimensions of the project are represented: 1) the participatory process shaping the intervention; 2) the products resulting from the process; and 3) the baseline of our intervention.

The participatory process

A visual and descriptive summary of the participatory process of shaping the integrated care pathway is given, resulting from interviews, direct observation sessions, and artifacts' analysis. In addition, a thematic analysis was performed of the interviews with group members. A reasoned sampling was applied to include the different professions (doctors and nurses), roles (organizational and clinical positions), and departments (emergency department and palliative care service).

The products

A visual and descriptive summary of the official document describing the integrated care pathway is given. The summary describes its main actors, their relationships and expected actions (Figure 1).

The work group's selection of clinical pathway monitoring indicators is presented in the form of numerators, denominators, expected outcomes, and data collection methods (Table 1).

The baseline of intervention

In this paper, we tried to establish a credible baseline for future evaluations that will monitor changes and generate hypotheses on the impact of the intervention. A questionnaire was administered to all active

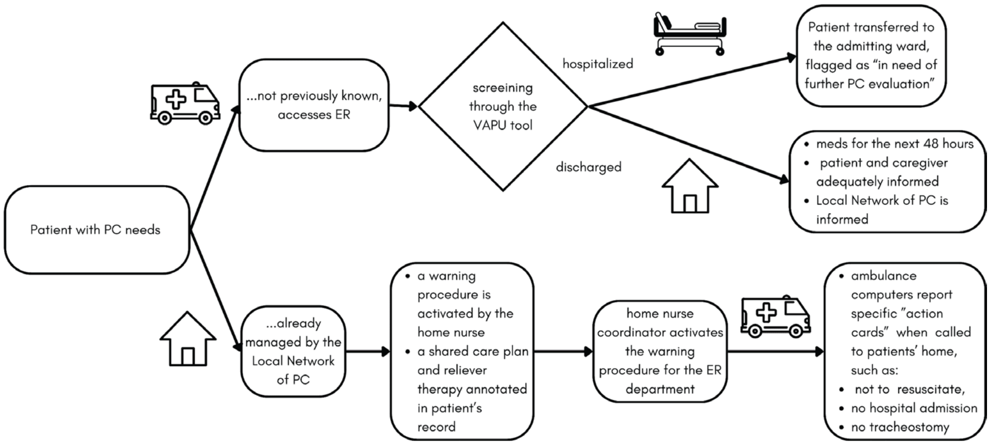

Figure 1. Integration between Local Palliative Care Network and Emergency Departments in the Local Health Agency (AUSL) of Modena, IT. (†) PC: Palliative Care; (§) ER: Emergency Room.

Table 1. Indicators for the evaluation of the clinical pathway.

Indicator description	Source	Ideal periodicity of observation
Number of patients that the ED referred to the LNPC	Electronic medical record of home-based care (“ADI-web”)	monthly
Number of patients assisted by the LNPC that accessed the ER / patients assisted by the LNPC because of the referral of the ED	Electronic medical record of home-based care (“ADI-web”)	every 3 months
Number of filled “VAPu” forms	Electronic medical record of the ERs (“Aurora PS”)	every 3 months
Number of patients assisted by the LNPC thanks to the referral from the ED / total number of patient assisted by the LNPC	Electronic medical record of home-based care (“ADI-web”)	every 3 months
Number of ambulance’s access to the homes of patients assisted by LNPC / patients that activated the “warning procedure”	Electronic medical record of home-based care (“ADI-web”)	every 3 months
ER accesses by patients that activated the “warning procedure”	Electronic medical record of home-based care (“ADI-web”)	every 3 months

staff members, either physicians or nurses, of the Local Palliative Care Network and the Emergency Department. The questionnaire assessed perceptions of palliative care use, knowledge of clinical pathways, and attitudes toward the use of medicines in specific emergency palliative care scenarios (see Table S3). Recurrent administration of the questionnaire is expected at T1=12 months and T2= 24 months.

Ethical considerations

Interviews with group members were a standard part of our health agency’s quality improvement project evaluation process and were administered only to professionals involved in the project. Anyway, data treatment and privacy authorization, along with the possibility of reporting the data in an aggregated and anonymous way in a paper describing the action research, were asked by the interviewees by the interviewers, and a written consent form has been collected.

The questionnaires were administered anonymously, and the recognition of the interviewee was not possible in any way.

Ethical approval was therefore not necessary, according to our local legislation.

We preferred to ask our Ethical Committee if any additional procedure was necessary to go on with this kind of study, and they confirmed no further authorizations were required in an official email dated July 18th, 2022.

Results

Visual summary of the participative process

The working group had a varying degree of participation, but we can describe it through some milestones, represented in Figure 2. Table S1 provides a textual description of the participative process in greater detail, as we interpreted it triangulating interviews and direct, non-participant observations.

Thematic analysis of interviews with the working group members

Eleven working group members were interviewed. Four themes were identified. In Table S2 a theme map

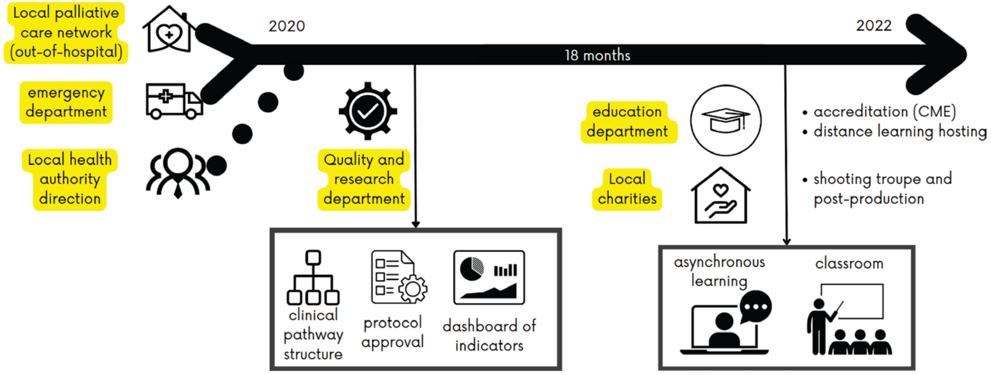

Figure 2. Milestones of the participative process.

and thorough description of inclusion and exclusion criteria and verbatim can be found. The four themes are identified in the following description.

- Better care for patients: most practitioners believe that "respecting the patient's wishes and clinical care needs is crucial" (int. 5) in order to achieve appropriateness of care and the ethical principles of Autonomy, Beneficence and Non-maleficence. Respect for the patient's wishes also comes through the choice of the correct setting, that is, reducing the so-called "improper ER admissions". The various professionals see the creation of this procedure as the perfect tool that can reposition the patient as a central figure in the care process.
- Better care for professionals: interviewees highlight how the procedure and legal elements already in place serve to protect the work of healthcare professionals by connecting two different realities that often deal with patients at the final stage of illness. In addition, it is emphasized that a "constant and continuous training" (int. 2) is an essential element to avoid the difficulties that professionals may encounter during their clinical activities.
- Palliative care culture: in several interviews, there is an awareness of the existence of different worlds, with seemingly "different vision and mission" (int. 6), and problems of mutual intelligibility, but mostly an effort is present to try to understand how to overcome these differences in order to collaborate towards a common goal. The need to increase "awareness of palliative care" (int. 2) in the emergency setting and the need for a common language, which can only be achieved with cultural upgrading, are often reported.
- Procedure's drafting and implementation: the most frequently enumerated reasons among those that slowed down the drafting of the procedure were the "bureaucratic time of registering the procedure" (int. 8) and the logistical difficulties of meeting due to the numerous commitments of the drafters, worsened by the restrictions for the COVID-19 pandemic. As for future obstacles, "obstructionism by some practitioners" (int. 3) was speculated: at first, the procedure might not be applied due to inadequate training. Some respondents also bring up the risk of different treatments for cancer patients and non-cancerous patients. This is because for the second type of patients "the prognosis is less predictable and therefore it is more difficult to involve the palliative care team with the right timing" (int. 4) Regarding transferability, the feeling that the procedure is transferable to other realities predominates in the interviews; indeed, it emerges that many realities are already adopting solutions on their own.

> Some operators, while considering the procedure transferable to other realities, are keen to point out that the procedure was developed based on the reality of the province of Modena, with its very specific characteristics (e.g., the homecare palliative network) that may not be present in other realities.

The products

An official document resulted from the 18 months of activity of the working group, along with a training program and a dashboard of indicators. A more detailed description of the actions needed by the health professionals, according to the official document, is available in Table 2.

Visual and descriptive summary of the clinical pathway

The clinical pathway structure is visually summarized in Figure 1.

The official document has many specifications, but we can describe it through some main paths, represented in the figure:

- a patient with PC needs may access the ER department without any previous acknowledgement of these needs by the Health System. If so, the patient is unknown to the LPCN. In that case, a first assessment of PC needs is performed in the ER department, using an ad-hoc screening tool (VAPU).
- if the patient is discharged, the nurse coordinator of the ER department, after providing adequate information to patient and caregiver, is going to inform the LPCN in the next 48 hours, so that the patient can be evaluated soon by the PC home assistance team. Table 2 reports examples of decisions that can be notified to the local emergency system.
- if the patient is admitted to the hospital, the PC need assessment is passed to the admitting

Table 2. Actions needed by the health professionals, according to the official document.

Palliative care staff actions required to activate ER staff	
Home Medical Record should contain	Entries describing the path of awareness and sharing of end-of-life decisions with patient and its family
	Creation of the document "Shared Care Planning" with patient's signature, or the "Advance Care Planning", with the involvement of the chosen fiduciary
	The medical treatments for symptom management
	Training for patient and its family in ER call
	The pre-filled form required from the ER service to officially enroll the patient in the procedure, carefully completed
ER staff actions required to activate Palliative care staff	
When patient is being discharged, the emergency doctor should perform:	Clear communication with patient, caregiver and family
	Checking the presence an appropriate caregiver
	Ensure that symptoms are steadily under control with a correct medical treatment and provide the necessary medications for 48 hours
	precise medical report regarding the ER access
	Contact by phone the local palliative home care service's office to ask the enrollment of the patient in their service
Patient target to the local emergency system	
Patients are aware of the prognosis and have expressed the following wishes:	Not to be intubated or resuscitated in case of critical event.
	Not to be hospitalized in case of having expressed its preference to spend their end-life stage at home
	to receive medical treatment to relieve symptoms (including palliative sedation)

Table 3. Results of palliative care questionnaires submitted to emergency department professionals.

<table>
<tr><td colspan="7">How do you rate your knowledge of palliative care topics, from 1 to 5 (1 being "very little knowledge" and 5 being "very much knowledge")?</td></tr>
<tr><td>Knowledge rating</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>tot</td></tr>
<tr><td rowspan="2">Nurse</td><td>9</td><td>30</td><td>46</td><td>15</td><td>3</td><td rowspan="2">103 (100%)</td></tr>
<tr><td colspan="2">Negative: 39 (38%)</td><td>Intermediate: 46 (44%)</td><td colspan="2">Positive: 18 (17%)</td></tr>
<tr><td rowspan="2">Physician</td><td>1</td><td>3</td><td>10</td><td>15</td><td>3</td><td rowspan="2">32 (100%)</td></tr>
<tr><td colspan="2">Negative: 4 (12%)</td><td>Intermediate: 10 (31%)</td><td colspan="2">Positive: 18 (56%)</td></tr>
<tr><td colspan="7">How do you rate your department's response to patients with palliative needs from 1 to 5 (1 being "very little adequate" and 5 being "very much adequate")?</td></tr>
<tr><td>Department's response rating</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>tot</td></tr>
<tr><td rowspan="2">Nurse</td><td>12</td><td>37</td><td>41</td><td>12</td><td>1</td><td rowspan="2">103 (100%)</td></tr>
<tr><td colspan="2">Negative: 49 (47%)</td><td>Intermediate: 41 (39%)</td><td colspan="2">Positive: 13 (13%)</td></tr>
<tr><td rowspan="2">Physician</td><td>2</td><td>7</td><td>15</td><td>11</td><td>0</td><td rowspan="2">35 (100%)</td></tr>
<tr><td colspan="2">Negative: 9 (26%)</td><td>Intermediate: 15 (42%)</td><td colspan="2">Positive: 11 (31%)</td></tr>
</table>

ward, and the patient is flagged as "in need of further PC evaluation".

- The clinical pathway considered the needs of the PC patients already in the LPCN, too: home PC nurses can activate a specific warning procedure for their home-assisted patients. They need to have their reliever therapy and an official shared care plan registered in their home records. After this, the home nurse coordinator communicates to the ER department through a specific warning system the name and the choices of the patient. When and if an ambulance is called at the patient's home, the ambulance computers are going to report specific "action cards" such as "do not resuscitate", "no hospital admission", "no tracheostomy", and so on. Table 2 lists the actions required of home-based palliative care staff in order to activate the "warning" and of ER staff in order to activate the out-of-hospital PC services.
- a patient with PC needs may access the ER department without any previous acknowledgement of these needs by the Health System. If so, the patient is unknown to the LPCN. In that case, a first assessment of PC needs is performed in the ER department, using an ad-hoc screening tool (VAPU).

The clinical pathway monitoring indicators resulting from consultation between the working group and the Quality and Research Department are listed in Table 1.

The baseline of intervention: the questionnaires' results

As reported in Table 3, 135 questionnaires were completed by emergency department professionals, including 103 nurses and 32 physicians, from a total of about 500 professionals, including about 100 physicians. Most ER professionals at T0 agree that contact with patients with palliative care needs is frequent. Physicians rated their own knowledge of palliative care as "high" in a higher percentage (56% positive ratings) than nurses (17%), just as they rated more positively the response given by their department to palliative care needs (31% positive ratings from physicians, vs. 13% from nurses). This analysis points out a not unexpected finding of a gap between physicians' and nurses' perceptions of knowledge and adequacy of responses for palliative care needs, a possible obstacle to widespread "cultural" change.

Discussion and conclusion

Summary

Improving the provision of PC to ER patients is a challenge in modern health systems. We wanted to describe a possible model of intervention to improve the quality of care in a participatory way through the development of an integrated care pathway. We described this quality improvement project through the description of the participative process, the results of a preliminary questionnaire on palliative care in the ER department, and the organizational improvement that the work group collectively decided on.

Interpretation

How can you say if action research is successful? According to Hart (18), the participant group itself establishes the goal and the success of a "professionalizing" participatory action-research.

The working group aimed to create a clinical pathway that responded to the specific characteristics of our system and environment; therefore, a participatory approach has been chosen. Despite the fact that more time and data are needed to evaluate the impact of the intervention, we can assess the results of this first part of the process as an appropriate response: this action-research succeeded in building a participatory process that actively involved many actors from different departments and reached a high number of professionals in its training sessions, resulting in an official clinical pathway and an evaluation plan based on process indicators . None of the above stages were in any way considered part of mandatory training or mandatory activity for the staff. But the topic and the involvement of the actors produced a high level of participation in these preliminary actions.

Current evidence clarifies that the integration of ED and PC is highly desirable for its impact on discharge rate from the ER, reduced improper hospital admissions, reduced hospital stay for PC patients, and timely assessment of PC needs and referral to hospice care. However, it's not clear which model is best. Considering the high complexity and local variability of palliative care, one option could be the use of a participatory process involving local, motivated staff from both sides (ED and PC) with proper institutional support to develop a sustainable solution. In our specific case, this process successfully led to the goal we aspired to.

Limitations

As for reflexivity, three of the researchers involved are palliative care doctors (PV, FI, GM), one has a robust research background in palliative care and organizational research (GM), two have long experience working in ER departments (FI and CC). The action research process delivered the desired output, though we are still not able to provide clear data on the final outcome of what we designed and implemented. The purpose of the present paper was to describe the participatory modeling of the integration of PC and ED. However, a thorough quantitative and qualitative evaluation of the implemented process is imperative throughout its future developments.

The process we described proved effective in developing a structured, multicomponent response to the need for PC-ED integration. It is widely acknowledged that a mainly qualitative process of action research can provide insightful suggestions to stakeholders interested in developing similar interventions (17). On the other hand, it is equally accepted that this kind of evidence has a low level of generalization, as every local context has its own specificities and variables (17).

Conclusions

We developed a local response to the relevant problem with the integration of PC and ED in responding to the needs of PC patients. To do so, we used a participatory model that relied on the ability of motivated members of the already-available staff to highlight real-life problems and find appropriate, locally sustainable solutions.

We believe that our action research might provide useful, actionable advice to stakeholders interested in such solutions, but only the strong motivation of the professionals involved made this process possible, along with the appropriate institutional support, and both of these characteristics cannot be taken for granted in such a process. We hope for more future evidence on models of integration of PC and ED, but we believe that in the meantime, participative solutions might grant an adequate response to the palliative needs of patients in emergency settings, and therefore we are going to continue documenting and researching the impact of the solution we built and its future developments.

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Conflict of interest statement: 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.

Authors' contribution: All authors have: made a substantial contribution to the concept and design of the article, the acquisition, analysis, and interpretation of data for the article; drafted the article and revised it critically for important intellectual content; approved the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. RL, CL and MG curated the editing of the final draft; MG curated the methodological aspects, RL curated the submission.

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Appendix – Supplementary files

Table S1. Textual description of the participative process.

Twenty professionals from both the Emergency Department and the Local Palliative Care Network (LPCN) volunteered to participate in a working group to build the clinical pathway, with the approval and support of the Local Health Authority Direction.
Throughout the entire process, the quality and research department provided adequate support to produce the official document, have it approved, and build a dashboard of indicators agreed upon with five members of the working group for process monitoring. The official document was authored by 21 professionals.
The educational intervention was supported by the Educational Department in terms of Continuing Medical Education (CME) provision, communication, logistic support, and management of online training, while 14 members of the working group took care of content production.
A local charity supporting palliative care provided a team of professional video makers to produce shootings illustrating the practical implication of the clinical pathway in real working environments (e.g., real colleagues in the actual ER ward administering the VAPU ("Valutazione Palliativa in Urgenza", Palliative Evaluation in the Emergency Department)

Table S2. Themes delimitation, theme map and verbatim

FOR WHO? TARGET POPULATION
1. BETTER CARE FOR PATIENTS Inclusion Criteria: This theme includes all the parts that talk about the patient's health care, finding out as good practice the respect of the patient's will and needs, the best setting of care, avoiding inappropriate access to the emergency room. Exclusion Criteria: We have ruled out all the medical and lawful aspects, the consequences in civil and criminal matters result in not respecting the patient's independence (or independence principle) and to perform therapeutic persistence. **Verbatim:** • Interview 5: "[Among the elements in common among the procedure's drafters] The "patient-centricity," that is, respecting the patient's wishes and clinical care needs, is crucial, without forcing decisions that could go against his will." [...] "I hope finally for the chance for each person to self-determine. Without other people affecting what your choices are." • Interview 6: "The goal is the best possible management of the patient in the most appropriate setting, which in 90% of cases is not the hospital." • Interview 10: "I expect not to see in ER patients followed by palliative care, to be able to manage patients properly at home as well. I also expect an increase in referrals of new patients to the local palliative care network."

2. BETTER CARE FOR PROFESSIONALS

Inclusion Criteria: this theme includes all the elements that interviewees consider as guarantee of professional protection, such as:
- creation of structured way for an effective link to emergency department and palliative care, so as not overlap but make complementary roles of two entities;
- the need of training courses how means necessary to spread the best implementation of procedure;
- the medical and lawful aspects, all the parts in the interviews where it refers to legal grounds that inspire the authors for creation of procedure (law 219/17) and the parts to highlight the importance to do not overlap the liabilities (prescription and dosing) of physicians and nurses.

Exclusion Criteria: we didn't consider the practitioner's complaints for red tape faced and we didn't consider underlines the importance to build a palliative care culture, that it is placed on a different level.

Verbatim:
- Interview 7: "a shared need to create a structured pathway to all those patients who "improperly" access ER not knowing any possible alternative in the primary care setting [...] A necessity to have a pathway that protects these patients, each professional from his point of view, and for his part of expertise."
- Interview 10: "When the ED professionals enter the scene, they have to try not to interrupt an already shared pathway, not to break the chain." [...] "Everyone, primary care, GPs, and ED, will have to follow the procedure correctly. So we will have to optimize training."
- Interview 2: "there is a lot of turnover in the ER so constant and continuous training must be ensured."
- Interview 3: "it will be important to involve (through training) the local health community to show the opportunities the project provides."
- Interview 9: "It was necessary to give a clear tool to all actors and to all recipients of this procedure so that in particular situations they are not alone or in difficulty and the system works better."

HOW?**S** MEANS/TOOLS

3. PALLIATIVE CARE CULTURE

Inclusion Criteria: this theme includes interviews parts of relevance to build a common language for the different practitioners with different points of view (emergency clinicians, palliative and general practice, physicians and nurses), through a cultural upgrade in palliative care.

Exclusion Criteria: there are not included the interview's sections that talk about technical procedures and project growth.

Verbatim:
- Interview 6: "There were somewhat different vision and mission, but that's to be expected, however, the added value was that we were all very motivated by achieving that goal, we saw that it was a need for all the operators, both from one side and the other. The confrontation also made it possible to eliminate those prejudices that are quite typical of those who work in one system and do not know the other. We just needed those who would explain one point of view in the other's words."
- Interview 10: "It was a great experience. We didn't know them, and they didn't know us, so the interesting part of having written this procedure was getting to know each other and understanding that palliative care and ER are not two separate worlds, but they come together. There has to be synergy between the two departments, and the goal is best practice for the patient."
- Interview 2: "I noticed that in the ER there was and still is a very low awareness of palliative care and end-of-life issues, even less about the quality of death. As health care providers, we have a very low sensitivity to these issues, so when I heard that the palliative care unit existed, I immediately got in touch with them; some ideas were born, and I asked to participate in their implementation."
- Interview 3: "within 6-9 months I expect a very good response of acceptance [...] I think there will be a physiological phase of adaptation, followed by a more proactive one, because a need will be recognized that now often cannot be identified."

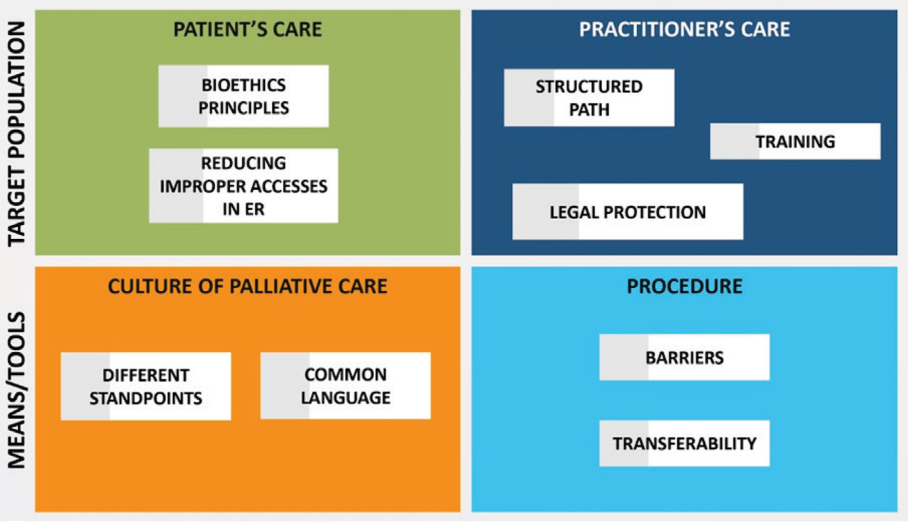
4. PROCEDURE'S DRAFTING AND IMPLEMENTATION

Inclusion Criteria: this theme includes all the parts where interviewees talk about barriers and **facilitators** for writing the procedure, but also the possible future obstacles for the application of the procedure. So, we have included the parts that analyze procedure's transferability to other realities.

Verbatim:
- Interview 8: "The pandemic blocked everything; home care was shifted to COVID-19 management. There was no chance for the group to meet, and that was a great obstacle. Other hurdles: when we got to the end of the drafting process, we realized that there were still bureaucratic time of registering the procedure, or for the possibility of accreditation of the operator training course or the difficulty of finding rooms large enough for all the learners (>500), so we decided to hold additional subsequent editions of the training in 2023." [...] "[Transferability] is possible. There are all the prerequisites from the theoretical point of view because there are legal preconditions."

- Interview 8: "It's necessary to say that in every district there is at least one ambulance with nursing staff on board, who assesses and treats patients according to regional guidelines and/or local procedures. It is also thanks to this that the procedure can work: in fact, if there were only non-medical volunteer staff, patients would be treated with BLSD protocol or transported to the hospital. This small detail makes the difference."
- Interview 3: "I have been saying for decades now that what has been done in the province of Modena is replicable on other territories." [...] "When [the procedure] comes into full force, I initially expect obstructionism from some practitioners, resulting from a lack of knowledge, then I count on a recognition of palliative care's roles in care processes.
- Interview 4: "I believe that on the non-cancerous patient there will be a lot of work to be done, e.g. nursing home residents, neurological patients, pediatric patients, etc... for these types of patients the prognosis is less predictable and therefore it is more difficult to involve the palliative care team with the right timing for proper care and quality care."

Abbreviations: ER: Emergency Room; ED: Emergency Department; GPs: General Practitioners.



Thematic groups emerged from interviews with the working group members.

Table S3. Questionnaire about perceptions of palliative care use, knowledge of clinical pathways, and attitudes toward the use of medicines in specific emergency palliative care scenarios.

Perception of palliative care provision:

1. How often in your work do you meet patients with palliative care-related needs?
   a. never
   b. episodically (few cases/year)
   c. at least monthly
   d. at least weekly
2. How do you rate the emergency-urgency department's response to patients with palliative care-related needs from 1 to 5 (1 corresponds to "very poorly adequate" and 5 to "very much adequate")?

1	2	3	4	5
Very poorly adequate	Poorly adequate	Adequate	Very adequate	Very much adequate

3. How do you rate your expertise on palliative care topics, from 1 to 5 (1 corresponds to "very little knowledge" and 5 to "very much knowledge")?

1	2	3	4	5
Very little knowledge	Little knowledge	Average knowledge	Much knowledge	Very much knowledge

Knowledge about palliative care pathways:

4. In the AUSL (local health departement), specialized palliative care is provided by:
    a. palliative physicians
    b. a team, which includes at least one physician and one nurse practitioner
    c. a team, which includes at least doctor, nurse, psychologist
    d. all those who care about the dying patient's best interests

5. The task of the PUASS (Place of Socio-Health Care) in the current organization of hospital palliative care is:
    a. to receive and manage requests for the palliative care team evaluation
    b. none: it deals with community services, not hospital services
    c. to provide the operative units with specialized palliative care medications (sedatives and analgesics)
    d. To maintain communication with family members of patients in the palliative care network when they are hospitalized

6. The activation of "Integrated Home Palliative Care" (ADI Palliative Care) involves all but one of the following. Which one?
    a. the patient is taken care of at home by the palliative care team, which may include physicians, psychologists, nurses, social workers
    b. the patient is seen at intervals set by his or her general practitioner, according to a contract established at the opening of integrated care
    c. the patient receives medication at home instead of having to get it from the pharmacy
    d. the patient must have agreed to no further hospitalization in order to be taken care of by home palliative care

Knowledge in palliative care:

7. Which of these pharmacological solutions do you think is most appropriate for sedation of a palliative care patient presenting with a "refractory" symptom?
    a. Initial 5 mg midazolam, then 30 mg midazolam in 24 hrs elastomeric pump and possible additions as needed
    b. 40 mg morphine in 24 hrs elastomeric pump, assessing risk of respiratory depression and arranging for naloxone at home
    c. 5 mg midazolam SC, repeated as needed in case of awakening
    d. propofol in continuous infusion, 0.5-1 mg/kg

8. A patient with ALS shows clear signs of dyspnea, so your emergency service is activated. When you assess him, he is unable to express himself clearly; however, he has left a document drafted in the presence of the palliative care specialist in which he clarifies that he does not want to be intubated. Which intervention is appropriate in emergency?
    a. if the patient is unable to express himself in that moment, hospitalization and temporary intubation remains appropriate, to be followed by possible extubation under sedation if the end-of-life pathway is confirmed ethically and medico-legally
    b. initiate symptom control treatment with morphine, and in consultation with family members explore the possibility of continuing at home
    c. initiate symptom control treatment with high-flow oxygen therapy and rhino-tracheal suctioning (with possible use of cough machine if provided at home), and in consultation with family members explore the possibility of continuing at home
    d. d. appropriate intervention is decided in consultation with the family member present, if they are aware of the patient's overall situation and history

9. You are called home to a patient in palliative care network care, dying, with SC elastomeric pump with morphine and sedatives, because relatives are distressed by the very loud breathing noise. What may be the first pharmacological option to be evaluated?
    a. furosemide 25 mg bolus, and addition of 25 mg in the elastomeric pump
    b. butylscopolamine 60 mg over 24 hours
    c. gradual decrease of morphine (due to the effect of respiratory depression that decreases expulsive capacity), while maintaining monitoring of other symptoms, especially pain
    d. areosol with beclomethasone, N-acetylcysteine and saline solution, to be repeated at least three times daily if effective

10. In properly prescribed morphine pain therapy, which of these dosages can NOT be found in the medical record?
    a. 4 drops every 4 hours
    b. 10 mg EV at 9 a.m. and 9 p.m.
    c. SC elastomeric pump with 20 mg morphine/24 hours
    d. EV elastomeric pump with 20 mg morphine/24 hours