



## Lay Summary

### Communication skills in end-of-life care

#### Project team

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Lausanne, April 10

## 1. Background

Over the last decades, communication has increasingly become a focus within medicine, and patients' expectations have evolved: while in the past a paternalistic model of medicine has prevailed, nowadays patient's autonomy, patient-centered care, shared decision-making and empowerment have become central elements of care. This evolution implies a great deal of communication between patients and clinicians, a task for which clinicians are often not adequately prepared; this is especially the case when it comes to communication with severely ill patients who are at the end of their life. As a consequence, end-of-life (EOL) care has been developed as a specific field, closely related but not uniquely associated with the emergence of palliative care and the consciousness that dying patients represent a vulnerable population with specific needs.

High-quality EOL care therefore heavily relies on adequate communication between clinicians and patients. However, EOL communication not only depends on clinicians' skills or abilities, but also on their psychological state when facing patients at the end of their life, and consists of cognitive, emotional as well as relational elements. Multiple barriers moreover exist in daily clinics hampering adequate communication with the terminally ill patient and his/her significant others. Some of these barriers – to name a few – are related to (i) the “inner world” of the clinicians, such as fear of addressing issues, the emotional state of the patient or his/her worries with regard to the end of life, but also uneasiness due to a lack of experience and competence in EOL care or (ii) contextual factors, such as institutional constraints (available time, inadequate settings, overspecialization and fragmentation of care or society's dominant discourses about death and dying).

Due to an increasing awareness of the importance of communication and the high prevalence of communication challenges in settings like oncology or palliative care, so-called Communication Skills Training (CST) programs have been developed and implemented to promote and enhance skills of medical students and clinicians. In postgraduate education, they have been most widely implemented in oncology, and even declared mandatory in certain countries, such as Switzerland, for physicians specializing in medical oncology. CST programs have greatly contributed to raise awareness about communication issues within medicine, and results from research showing alarming problems in clinical communication have helped to put the topic of communication on the educational agenda of medical societies, such as the Swiss Society of Medical Oncology or the European Society of Medical Oncology, with the effect that they started to promote attendance to CST and to encourage clinicians to actively seek to improve their communication abilities. Meanwhile, CST programs have been implemented in many countries, most often addressing communication in the oncology or palliative care setting: the Swiss CST program, as stated above, has been declared mandatory for the specialization in oncology and the Swiss Society of Palliative Care has formulated recommendations for their members concerning continuous education in clinical communication. Based on the literature, such programs need a minimum of duration (at least 2-3 days), they should be conceived with the aim to promote participation and interactivity of participants, and they should be conducted in small groups of not more than 10-12 clinicians. The main ingredients of postgraduate CST programs are role plays, analyses of videotaped interviews with real or simulated patients and group discussion about difficult clinical situation. Such training has been demonstrated to enhance certain communication behavior: e.g., the number of open questions or silences, empathic statements or adequate provision of information. Also at the undergraduate level, teaching of clinical communication has been introduced using different methods, such as small-group discussions, analysis of videotaped patient interviews, communica-



tion exercises with real patients and videotaped interviews with simulated patients for individual or group supervisions. Research on CST programs at the undergraduate level is just emerging and it is too early to comment about their effects.

While the developments presented above are welcomed, criticisms against traditional CST programs have also arisen over recent years. These criticisms can be summarized as follows: (i) there are conceptual and theoretical problems associated with CST – e.g., ‘effective communication’ is not defined; a conceptual framework of CST is generally missing; to consider clinical communication as a set of discrete skills is problematic; standardized methods for communication between clinician and patient may result in feelings of de-subjectivation and alienation by the patient –, (ii) the exclusion of clinicians from the development and implementation of most CST programs hampers their potential to be learner-centered and to integrate clinicians’ lived experiences and resources; and (iii) CST programs have become more and more specific and generic aspects of communication tend to be lost.

## 2. Goals of the project

The objectives of the research were: (i) to develop a communication training curriculum based on clinicians’ lived experience and perceptions of training needs, which (ii) addresses the emblematic topic of death and dying that represents a general challenge to the clinicians regardless of their specialization, and (iii) takes into consideration the criticisms with regard to CST programs, thereby contributing to innovate and go beyond the well-known and widely implemented traditional CST programs.

## 3. Methods and results

*Since the project consisted of two phases, the second phase being inspired by the results of the first one, we will present methods and results together.*

The research approach was based on eight focus-group (FG) discussions with physicians ( $n = 28$ ) and nurses ( $n = 30$ ) of medical disciplines with a high prevalence of patients at the end of life, namely geriatrics, internal medicine, oncology, and palliative care; 4 FGs were conducted with physicians and 4 with nurses to ensure within-group homogeneity with regard to medical specialty and profession. The FG discussions explored:

- i. the training needs of participating clinicians and how they perceived their medical colleagues’ training needs when encountering dying patients;
- ii. clinicians’ representations of an ideal physician providing EOL care (his qualities and virtues).

While training needs were investigated with the objective to obtain experience-based information about competency gaps, representations of an ideal physician were explored to identify what physicians value and what they yearn for in EOL communication and care. Furthermore, expectations in terms of training format were elicited (e.g., setting, duration, qualities of trainers or degree of professional homogeneity of future trainees).

An inductive thematic analysis approach was used to analyze verbatim-transcribed FG interviews, and carried out based on the “immersion, reduction, and interpretation” process model. Audio-taped interviews were listened to and transcripts iteratively read to identify relevant themes and patterns of meaning with



respect to the explored phenomenon (immersion); a coding frame was devised, based on data-driven codes, to classify, understand, and examine the data (reduction); and, finally, salient patterns of meaning present in the data were highlighted (interpretation).

Based on the results of these FGs, the training we developed, which we call *Clinician Reflexivity Training* (CRT), has been influenced by different concepts, of which we will only discuss two. First, after years of teaching and researching on CST programs at the under- and postgraduate levels, we have shifted in postgraduate training from skills and techniques to the “inner” world of the clinicians, especially clinicians’ anxieties, defensive attitudes and other intra-psychic processes. This shift is anchored in a psychodynamic understanding of the physician-patient interaction, which also takes into account relational aspects, including unconscious elements. Second, these experiences led us to also adopt a comprehensive framework of communication, which includes the role of the clinician’s psychology, but also his lived experience, his socialization, and other contextual factors, be they institution- or society-related. This framework is thus embedded in the realm of the medical humanities, which have multidisciplinary roots, including sociology, psychology, anthropology, philosophy, and linguistics; we try to integrate these dimensions in our work.

The evaluation of training was inspired by a questionnaire for the evaluation of Balint groups. In Balint groups, a clinician presents the situation of a patient, followed by a discussion with peers; the scientific evaluation of Balint groups addresses the possible gain of consciousness and change of participants’ attitudes and values, an increase of awareness about clinical relationships and introspection. The questionnaire administered online five days after training contains ten items, including statements such as: *I have realized that my emotions and reactions may influence the care and the relationship I have with patients at the end of life* or *I have become aware that some reactions of the patients at the end of life are confronting me with my personal lived experience*.

We have observed a rapid booking of all training courses (four courses in 2014 and one in 2015), and an almost complete return rate of the evaluation questionnaire (about 95%), showing high satisfaction of participants with training, and a change of attitudes towards death and dying, confirming that a process of introspection has been initiated. Moreover, the training is now locally anchored by means of the cooperation with UNIL-EPFL advanced continuing education and will be repeatedly provided over the next years; train-the-trainer courses will be proposed in the years to come to allow a larger implementation (other areas of Switzerland).

Based on the results of the before mentioned focus-group discussions and the first experiences with the Clinical Reflexivity Training (CRT), we observed that certain topics were not voiced when exploring clinicians’ perceptions and attitudes towards EOL communication. However, we know that physicians are subjected to various influences – undeniably shaping patient care and physicians’ lived experiences –, which remain thus partly or totally scotomized. These scotomized influences are related to the health and emotional life of physicians, their socialization, the health care context, and the society.

Consequently we aimed in a second step to empirically examine unvoiced topics, and to assess how they affect the physician. We thus investigated (i) the “inner world” (psychic) of physicians who care for dying patients and (ii) their perception of the constraints they face in daily practice (lived experience of the “out-



er world”). The interview guide consisted of four types of what we call ‘facilitators of narratives’, which address specific aspects of the lived experience of physicians:

- <sup>1</sup> the social discourses on medicine, disease, physician, and patient;
- <sup>2</sup> the contextual factors related to the medical institution and apparatus;
- <sup>3</sup> the formation of professional identity (socialization-related issues);
- <sup>4</sup> their inner world.

‘Narrative facilitators’ were developed particularly on the basis of techniques inspired by visual sociology (e.g., photo elicitation) and clinical psychology (projective methods). They included (see pictures at the end of this lay summary):

- a press-book, consisting of eight booklets;<sup>narrative facilitator 1</sup>
- one photo-based story/storyboard, composed of eight *ad hoc* produced photographs featuring a working day of two physicians in a university hospital;<sup>narrative facilitator 2</sup>
- excerpts of physicians’ biographies, addressing topics such as medicine as a vocation, burnout, and empathy;<sup>narrative facilitator 3</sup>
- four blurred video sequences (not yet analyzed) from two documentary films [total duration = 2 min], which featured a physician who effectuates administrative duties, who visit a patient, moves within a group of other physicians, and turns in circle, alone in front of an elevator.<sup>narrative facilitator 4</sup>

Thirty-three physicians – chief residents and senior staff members – of Lausanne University Hospital were asked to comment on this material: 5 worked in geriatrics, 6 in palliative care, 10 in oncology, and 12 in internal medicine.

*Society’s discourse* | <sup>narrative facilitator 1</sup>

Participating physicians reacted to press articles in the booklets which featured different stories about medicine and physicians (only the most salient results are mentioned here):

Medicine in transformation

*Mutations*

There is an “old” and “new” profession of physician: e.g., the new profession requires the physician to be a good practitioner, a good politician, a promoter of himself and his/her hospital; nowadays medicine must defend itself against society and at the same time to sell itself to the public; or medicine undergoes an identity crisis: no longer highly prestigious, it has lost much of its importance.

*Shifting focuses*

There are constant changes in the medical field leading to reorganizations and arrangements: e.g., the focus of attention has shifted to the spiritual and psychological domains.

*The fall of the God in white*

The status of the physician has changed; e.g., the physician is no longer the “God in white” who knows best, he makes mistakes: “how to still trust him”?



### *The loss of humanity*

Medicine is now associated with research, progress and technology and is consequently des-humanized; physicians have become technicians.

### *Society's ambivalent stance*

The society has an ambivalent relationship with medicine; the public is both scared and fascinated by medicine.

### *Peoplization of medicine*

The focus of attention is on a rather triumphant medicine, very far away from clinical reality; there is a spotlight on the people, famous physicians, but not on the ordinary physician who does his job very well every day.

### *Contextual factors related to the medical institution and apparatus* | narrative facilitator 2

We provide here an example of reactions:

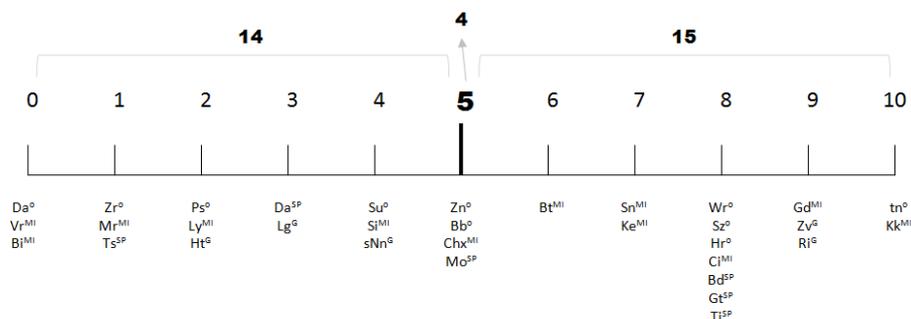
#### Internal state of the protagonists

The physicians referred to the inner experience of the main persons in the storyboard. They saw a motivated man going to work, a cheerful man or, in contrast, a harassed man starting his working day.<sup>photo 1, n=4</sup> Or they considered the person in his office as not being very happy, having annoying things to do, and carrying the burden of administrative tasks; an overloaded physician; or a physician who is not enthusiastic and who seems to be inefficient.<sup>photo 4, n=4</sup>

### *The formation of professional identity* (socialization-related issues) | narrative facilitator 3

With respect to the third narrative facilitator, physicians were asked to indicate to what extent they agreed with the quotes (10-point analogue scale; 0 = I totally disagree with this view; 10 = I totally agree with this view). In the figure below, physicians' names [Bb, Zv, Hr, etc.] were codified for confidentiality reasons; medical specialties are superscripted [O: oncology; G: geriatrics; SP: palliative care; MI: internal medicine].

The quote stating that physicians practice a medicine that they did not learn in medical school.



The analysis of the material produced by means of the fourth facilitator is ongoing; the interpretation of the final results will be integrated in the upcoming editions of our CRT.



## 5. Significance of the results for science and practice

High-quality EOL care relies on adequate communication between clinicians and patients. However, EOL communication not only depends on clinicians' skills, but also on their psychological state when facing dying patients – in a specific institutional and societal context – and consists thus of cognitive, emotional as well as relational elements.

In addition to the physician's "inner world" (psychic), the "outer world" (context) has important consequences on the physician, the patient-physician encounter and the practice of medicine. Based on our research project, we observed that physicians are only partially aware of the influences from the "inner" and "outer" world which shape their lived experience. Among these influences are, for example, the clinician's own emotions; the clinician's understanding of his professional role and identity; the clinician's socialization; the health care context with its institutional constraints and pressures; the public's collective beliefs, expectations or distrust towards medicine. We have assessed these dimensions in the first and second phase of the project and thus developed a constantly evolving training, which focuses on the clinicians' psychology (their "inner world") and the lived experience of the context within which they are working (their "outer world"). Our training does not provide advice or technical skills, but aims to set in motion an introspective process and a conscientization within the clinicians, with the aim to enhance their reflexivity, and to allow them to cope with their experiences and contextual constraints. First evaluations of the training, which we call Clinician Reflexivity Training, confirm that it reaches these aims.

In addition, the training in EOL communication we have developed within this project meets some of these neglected requirements. It is innovative, since it was developed with the participants; implemented by means of the cooperation with UNIL-EPFL advanced continuing education, the training is now locally anchored and constantly evolving (due to the results of the second phase of the research project, as well as observations in training and feedback from participants); train-the-trainer courses will be organized in the years to come in order to allow a larger implementation (other areas of Switzerland).

The physician being a central element in health care and a key actor when it comes to decision making and organization of care, to know more about the tensions related to his inner and outer worlds allows to (i) transmit a more realistic image of the profession in undergraduate training, to (ii) intervene on an institutional level, and to (iii) raise society's awareness of the profession of the physician. In view of the shortages of physicians and the many problems health care will face in the future (limited budgets, the need of competences which go beyond the knowledge of medicine, expectation for holistic care, increase of geriatric patients, etc.), this project will provide a basis to initiate physician-centered research and invite physicians and other health care providers not only to create and apply medical knowledge, but also to reflect on themselves, on their encounters with patients, on the institutional and health care context, and on medicine and its relationship with society. Some elements of this project, such as the narrative facilitators, have already been and will be used in pre- and postgraduate training (e.g.: optional courses for medical students of Lausanne University, postgraduate seminars for hematologists).

To conclude: research addressing the physician himself is very rare up to now and should be promoted. By focusing on physicians' lived experience and on the contextual constraints they face in daily clinical prac-



tice, our project has allowed to develop and implement an innovative training to improve communication in end-of-life care and to initiate a new line of research, which we call “physician-centered research”. We are currently submitting a new grant which deepens some aspects of this new line of research.

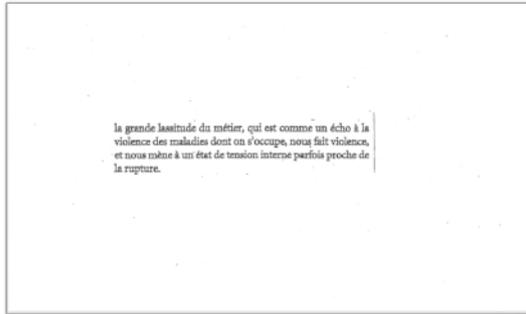
1 | *examples of booklets*



2 | *storyboard*



3 | *biography excerpts*



4 | *video sequences*

