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# FRENCH REFERENTIAL OF THE CLINICAL PRACTICES OF PSYCHOLOGISTS IN PALLIATIVE CARE

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## PLAN

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## INTRODUCTION

This document was developed from the French frame of reference<sup>1</sup> for psychologists working in palliative care. It aims to serve as a professional reference that will define practice guidelines for psychologists during palliative care treatment and identify what is specific to the psychologist's function and to this particular field of practice. It states in clear and relevant terms the benefits and limitations of the therapeutic offer. It defines psychologists' clinical practice, the stance they should adopt and the necessary conditions for carrying out their tasks. It goes beyond the usual scope of a competency framework to include a definition of attitudes and behaviour that provides a clearer account of the characteristics of the clinical encounter. The competencies of the psychologist are assessed with reference to all the relevant requirements such as training, research, and knowledge of specific concepts.

This document was drawn up to incorporate practices specific to other countries and cultures. Beyond the diversity of practice between countries and cultures a common approach by clinical psychologists can be identified from which a set of basic parameters can be extracted and formulated. These core elements are presented in the document to underline the rigour and consistency of the clinical procedure, which consists in a psychodynamic approach to the subject.

# A. GENERAL CONTEXT

## I. Historical background

Palliative care has developed in the last 40 years to provide comfort to patients suffering from serious or terminal illnesses; physical comfort, of course, but also psychological and spiritual. It follows on from a tradition of support for the dying and draws on established practice and expertise. Articles began to appear in the United States in the 1950s about the psychological impact of illness on cancer patients. The publications dealt with the psychological complexity of confronting death and the difficulty in presenting medical information and decisions to patients and relatives. Two distinct but complementary approaches emerged, psycho-oncology and palliative care. Psycho-oncology was developed in the work of researchers such as Jimmie Holland (2009) and David Spiegel (2000) from their concern about the psycho-social, environmental and ethical aspects of cancer.

One of the main pioneers of palliative care was Cicely Saunders. She founded the Saint Christopher Hospice in London in 1967, the first establishment specialised in palliative care. She gradually developed a new approach to care on the basis of her

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<sup>1</sup> Conçu par le Collège des Psychologues, Van Lander A. (Ed), (2016).  
Société Française d'Accompagnement et de soins Palliatifs (SFAP), [www.sfap.org](http://www.sfap.org)

research on morphine and pain relief, at the same time establishing the importance of listening and empathy. She conceived the concept of total pain, which is a physical pain that encompasses psychological, social and spiritual suffering (Saunders, 1995). She was influenced by the work of Carl Rogers, an American humanist psychologist, and by the Palo Alto school, and elaborated a theory of communication and relationships. In the same period, Elisabeth Kübler-Ross published “On Death and Dying” (1969) in the United States, in which she proposed a theory of the psychological reactions of patients confronted with death.

Psychologists’ current practice in palliative care has grown out of the previous experience of certain pioneering figures who were confronted with the particular problems of end of life care. These pioneers, irrespective of their profession, built their practice and works around a reflection on the mental life of terminally ill patients and that of their relatives and friends. One of their main areas of work was the fear of death and the defence mechanisms used to overcome it. Elisabeth Kübler-Ross theorized the changes in mental states of patients nearing death and characterized the defence mechanisms brought into play, such as shock, denial, anger, depression and acceptance. Her work long served as a reference, and for care teams shed light on the psychological processes of the end of life.

In current practice, psychologists take care not to adopt a single perspective, and have reinstated the value of defence mechanisms, situating them in the context of a relational dynamics. Psychiatrists and psychologists such as R.W. Higgins, M. Renault and E. Goldenberg have set up team supervision programmes to help health professionals better understand the complexity of the mental mechanisms of patients at end of life, and those of patients’ relatives, friends and caregivers.

Michel Hanus (1994) and Janine Pillot (1990) have carried out clinical research into mourning, suicide and death. Palliative care does not end with the death of patients, and bereavement follow-up of indefinite duration is now part of good practice.

## II. The psychologist and interdisciplinarity

Interdisciplinary work is one of the cornerstones of comprehensive palliative care. It is based on interaction between the different team members and on the sharing of information, knowledge and expertise. Each health professional, according to their discipline, contributes to the common action and sheds a specific light on what patients and their family circle are experiencing. A holistic view is combined with consideration of each individual case. The role of the psychologist in interdisciplinary activity is to bear witness to the mental life of the subject (patient, relative or close acquaintance) and to transmit this experience to achieve greater coherence of care.

The aim of this approach, which involves overall care of the patient and individual personalized support, is to enhance the singular nature of each professional’s contribution in an attempt to decompartmentalize care and encourage a comprehensive view. Joint discussions with caregivers and paramedics allow psychologists to relay observations about the mental dynamics of patients in a situation of suffering and at the same time to collect information and opinions about care treatment. Interdisciplinarity advocates holistic care. This, however, is neither

easy nor simple to implement. It involves overlapping of tasks, rivalries and issues of power and knowledge. The position of psychologists is paradoxical in that they occupy a place in the team while attempting to be distant from it, playing the role of an outsider in the group in the analysis and understanding of situations. Words such as multi-, inter- and transdisciplinarity are used to describe modes of team work and translate how different disciplines play their part. Multidisciplinarity is the juxtaposition of disciplines with no interaction or sharing in common. Interdisciplinarity is the collaboration of disciplines in the construction of a joint action, which sometimes makes a holistic approach difficult. Transdisciplinarity is the construction of a common language that is able to apprehend a situation in all its complexity. The term derives from interdisciplinarity (Nicolescu, 1993) and was probably first used by Jean Piaget at a symposium in the 1970s. The “trans” element takes us beyond and across the disciplines. The value of transdisciplinarity lies in the possibility of all members of the team to call upon the theoretical background of the psychologist in the performance of their tasks. While overlapping areas may exist they should not be allowed to result in a takeover of power or shifts in function. When the psychologist is absent the team falls back on its own expertise thereby creating symbolically the psychologist’s presence.

### III. The place of the psychologist in palliative care (*What is the psychologist’s status?*)

#### 1. Regulatory framework

The exercise of psychology requires a professional title and status. In Europe, psychologists are governed by the Charter of Professional Ethics for Psychologists, adopted in Athens in 1995 by the 29 member countries of the European Federation of Psychologists’ Associations (EFPA) at their general assembly and revised in February 2012. The Charter states that “Psychologists’ competence is derived from theoretical studies given at university at the highest levels and which are being continually updated, as well as from practical training qualifications which are derived from their education, training and personal experience, thereby establishing their own professional limits”.

#### 2. Institutional framework

The psychologist’s professional status does not involve a hierarchical relationship and allows a certain autonomy and individual responsibility. The principle of autonomy does not mean a desire for independence. Psychologists take part in interdisciplinary work, which entails a certain number of obligations like attending team meetings and communicating with different health professionals. They discuss the dynamics of the institution with management teams and consultants and chooses appropriate means of intervention.

In addition to civil and criminal liabilities, psychologists have a professional responsibility. Being bound by a contract with a private or public organisation in no

way changes their duties, in particular obligations concerning professional secrecy and the independent choice of methods and decisions.

Psychologists may be required to write an annual activity report, which is often included in that of the institution. The exercise is primarily qualitative and allows an assessment and analysis of the evolution of their practice. The report provides fellow workers in the institution and the management team with a clear picture of the psychologist's activity.

### 3. Tasks and ethical principles

- Patients' informed consent

The European Charter of Professional Ethics for Psychologists stipulates that a team's request to meet a patient does not automatically lead to patient management and follow-up. The request serves as an indication for making contact with a patient, who is thereafter free to accept or decline the proposal of interviews with a psychologist. Psychologists can intervene with patients only "with the consent of the individual concerned". They should distinguish between difficulties encountered by the team in patient management and the real need of a patient to receive care. Nevertheless, medical teams and physicians fulfill the role of facilitators in setting up patient interviews.

- Aim of the interviews

If a patient accepts to attend individual interviews *"the fundamental task of the psychologist is to ensure respect for the individual's mental dimension. The psychologist's intervention concerns the individual's psychological components taken singly or collectively and placed in their context"* (Chapter I, Article 2 of the French code of conduct). In palliative care, this task has the additional aim of "relieving the mental suffering" of patients. Psychologists share with the team the ethos of palliative care. They propose a different vision of medical and care practices in the light of psychological concepts. Paradoxically, psychologists must be aware of medical reality and then put it to one side when it comes to clinical interviews. They are divided between the team, the need to be informed about medical care, palliative medicine and an unbiased attitude towards patients.

- The third principle concerns **the notion of confidentiality**.

Interdisciplinarity involves communicating relevant information about patients to other health professionals, who enter into a contract that gives patients the authority to designate who, among professional staff and relatives and friends, should have access to this information. Psychologists refer to the European Charter of Professional Ethics for Psychologists to decide on what is appropriate to share or not. The passing on of personal information does not always respect the limits of confidentiality. Because patients are in care does not justify their privacy being invaded. The European Charter of Psychologists includes respect for confidentiality in its first principle concerning respect of the individual: "Psychologists guarantee confidentiality, respect and professional secrecy and protect the privacy of the individual even when they are required to pass on information regarding their work".

## IV. GENERAL DESCRIPTION OF PRACTICE ACCORDING TO DIFFERENT PALLIATIVE CARE STRUCTURES

Certain characteristics of practice are common irrespective of the professional setting.

- The psychologist proposes individual or family interviews to patients and their relatives.
- The psychologist proposes bereavement follow-up. The teams provide information about this support and can pass on the psychologist's contact details. In some institutions, follow-up is available to all bereaved persons, for deaths occurring outside the institution, for example, or in the event of a sudden death. Follow-up can be individual or conducted in groups. As the period of bereavement can vary, follow-ups are not of any predetermined duration. However, should any new major problem arise, the psychologist should call upon a colleague from outside to take over.
- Psychologists are committed to being involved in the different activities of the teams such as medical staff meetings, patient assessments, departmental meetings and meetings with the families in a medico-psycho-social approach. This interaction and co-operation forms the basis of the interdisciplinary functioning of the teams.
- Psychologists are accessible to all members of the medical and paramedical teams and to caregivers and volunteers for individual or group discussions about professional practice. However, they do not assume the position of supervisor of their own group and do not undertake personal follow-ups of fellow workers.
- Within the institution psychologists bear witness to the mental dimension of support and care. Hence, they sit on the different decision-making committees and sometimes on the ethics committee. These activities are organized as a complement to their clinical practice schedule.
- According to the time available to them, psychologists provide initial training and continuing education, thereby contributing to a greater awareness of the palliative approach.
- Psychologists keep their professional knowledge up to date by following training courses paid for by their institution.
- Psychologists develop a peer network including local and national colleges and supervision groups and attend meetings organized by regional, national, and international associations such as the European Association for Palliative Care (EAPC) and the International French Association for Palliative Care (FISP). These meetings reinforce their professional identity and promote collaboration in the follow-up of patients.

Psychologists may be requested to provide support for persons in palliative care or for their relatives, or for both, in different palliative care structures and also in other settings, where they will implement a similar approach.

## 1. On duty in a palliative care unit

Psychologists play an integral role in the department that provides care for the patients. They collaborate with the team in charge of care. Most patient interviews are conducted at bedside but the psychologist should nevertheless have an office. Its location should be clearly indicated along with the times at which the psychologist is available. Preferably, the office should be near the patients' rooms, where most interviews with the psychologist are held, and therefore of easy access for patients and their relatives and friends. The office should not be shared with other professionals but remain symbolically the dedicated place for the discussion of mental problems. Its invariant status provides a holding framework for the patient interviews.

Patients should be informed of the presence of a psychologist in the unit. Team members and the psychologist decide on how the information should be communicated, for example, by team members at reception, on posters or in leaflets.

The psychologist can decide to systematically meet patients and their relatives on their arrival in the unit. This formal introduction will make it easier for them to make a request for an interview at a later date. The psychologist is at their disposal and they are free to make an appointment if desired. Priority is given to the patient. Should there be requests from several family members, the psychologist will take care to differentiate follow-up as much as possible and make referrals to outside colleagues. Joint interviews with relatives or friends can also be arranged. Certain persons may already have had interviews with a psychologist before their arrival in the palliative care unit and may wish to continue with them. They are free in their choice of psychologist. The resident psychologist in the unit ensures that all requests are respected and, with the patients' agreement, will contact colleagues to achieve this end.

Palliative care units provide training and mentorship for psychologist interns and interns from other professions. The resident psychologist receives the interns individually and explains how relations with patients, relatives and team members are structured. The discussions touch on what attitude the intern will adopt when confronted with the problematic process of dying, how to establish communication, the emotional reactions engendered by contact with a dead person and the function of the psychologist in palliative care. The psychologist is at the interns' disposal to answer any questions they may have. The psychologist takes part in the recruitment, training and monitoring of voluntary helpers, closely surveying their ability to adequately deal with the problems encountered in the palliative care setting.

## 2. Transversal structures

The transversal approach leads the psychologist to collaborate with teams specialized in various fields, such as oncology and intensive care, who are sometimes based in outside establishments under contract with the unit. In collaboration with the different team members, psychologists are mindful of communicating the values and points of reference of palliative care. Sometimes, they

can support or help in taking a collective decision and take part in discussions of ethical issues.

a. Mobile palliative care team and identified palliative care beds

The mobile team intervenes in a wide variety of departments and institutions and the psychologist has therefore to take into account this diversity and be ready to adapt to the specific nature of each organization. In certain cases the psychologist will have to consult and coordinate with a counterpart.

The mobile team works in tandem with referral departments and their partnership is essential for ensuring the quality and consistency of care. The mobile team psychologist can also propose external consultations to patients or families, or to both, who make the request.

According to needs, the psychologist can offer psychological support, either individually or in groups, to hospital caregivers working in palliative treatment.

The psychologist has an integral role in teams managing identified beds and attends interdisciplinary meetings organized in the departments concerned. The meetings may deal with the daily care of a patient, and sometimes result in a collective decision. Because identified palliative care beds may be variously located within the same institution, the psychologist prioritizes interventions between meetings, requests for follow-up and other demands. Meetings can be arranged for the team following a difficult period of care or a series of deaths.

b. In the patient's home

Psychologists can be employed as a salaried member of a team and intervene directly in the patient's home or act as a coordinator and refer the patient to colleagues with a private practice.

They can take part in meetings with independent healthcare professionals, initiate discussion groups and propose individual aid for professionals in difficulty. They can also contribute to raising awareness of the palliative approach by organizing meetings and information evenings.

They can provide psychological follow-up for patients and their relatives and friends after the team has informed them of this option and how it operates. They must make sure that the conditions are clearly explained and accepted before going to the patient's home and, when necessary, be accompanied by a member of the team to give an explanatory presentation.

The psychologist must assess the feasibility of conducting interviews in the patient's home according to material conditions such as space and layout, confidentiality and the presence of other persons. If need be, appointments may be made elsewhere. Bereavement follow-up can be provided depending on individual needs.

The home setting is a specific area of intervention that requires adjustments. The locations visited may be geographically scattered and hence the number of individual interventions should take into account travelling time, which is included in working hours. The space-time created by long, repeated journeys can be conducive to reflection and analysis.

### c. Specific characteristics of paediatric palliative care

Palliative care for children depends on their stage of cognitive and psycho-affective development, socio-cultural environment and past experiences. It should be seen in a comprehensive biopsychosocial perspective. From the overall and singular evolution of each child, punctuated by spurts of maturity or bouts of regression and by interactions with the environment, there will emerge the ability to understand the severity of their illness, a manner of coming to terms with death, compliance with care and treatments, strategies for coping with symptoms, with pain in particular, and the ability to communicate with relatives and friends.

Against this particular background, the psychologist will attempt to acknowledge and take into account the different capabilities and limitations of the child with regard to their development and own temporality, which is sometimes very different from that of relatives or caregivers. The psychologist will contribute to the child's care and life project by attentive listening to what the child expresses verbally and by close observation of the child's behaviour, play activities and other means of expression such as painting and drawing.

The psychologist also intervenes in the mother/father/child triad. The way in which the father and mother react to their child's illness, the support and care they provide, the wishes they express for the child and the family unit are all elements that the psychologist has to take into account. The psychologist should also acknowledge the contribution and experience of each individual involved in the child's care. To ensure that the child does not become disorientated the psychologist, with the team of caregivers, supports the role of the parents, siblings, grandparents and friends in the family and social dynamics

The interventions of the psychologist in paediatric palliative care are prepared in conjunction with the members of the team and the psychologists involved in the child's welfare in order to help the caregivers in their support of the children and their relatives during illness and after death. The psychologist is attentive to the team members' emotional involvement. In the role of an outsider, exterior to the situation, the psychologist has a privileged situation that helps the team to step back and contain their emotions.

In palliative care, both before and after death, psychologists may have to move between the hospital and the child's home and school and when requested act as a coordinator and refer people to structures close to where they live.

One of their most important tasks is to raise the awareness of palliative care in health professionals and through training make them more familiar with the culture of palliative care and thereby better equipped to provide support for children and their families.

## V. CONDITIONS NECESSARY FOR CLINICAL PRACTICE

### 1. Supervision and analysis of practice

The European Charter of Professional Ethics for Psychologists states that the entitlement to exercise the profession requires a high level of theoretical knowledge that is acquired at a university and is constantly updated and, importantly, includes peer-supervised practical training. Given the acute nature of situations encountered in palliative care, the occurrence of transference phenomena and the confrontation with death, psychologists need imperatively to reflect on and analyse their professional practice.

Psychologists can feel powerless when faced with a subject's distress and lose the ability to properly elaborate their clinical practice. They then need to pause, and question and assess their practice by making a careful analysis or by requesting supervision. In sharing their experience, psychologists can step back and have a different view of the situation and as a result arrive at a new working focus or hypothesis. Supervision or analysis, or both, enhance the emotional and intellectual ability to live through difficult situations. The work of analysis can cast a new light on clinical activity and help to theorize practice.

Supervision offers the further possibility of analysing transference and counter-transference phenomena, and the psychologist's personal input in patient interviews and interactions with the teams. The psychologist opts for an individual or group approach.

### 2. Research

The status of a psychologist allows time for research. Clinical practice and research are closely intertwined: research provides roots and nourishment for the foundations of clinical practice while clinical practice validates research and at the same time questions it and sheds new light on it. In a field as sensitive as palliative care, which is in constant evolution, psychologists need research into their practice to keep abreast of new trends and developments. They can initiate their own research projects, take part in biomedical research and contribute to human science and public health projects.

In practice, the joint pursuit of research and clinical activity is far from being simple. On the grounds of ethical considerations, the fragility and vulnerability of patients are often put forward as reasons to hold back studies deemed to be too rigid, intrusive or impersonal. The desire to overprotect those who are suffering runs the risk of thinking and speaking for and instead of the patient and claiming the professional's concern for the patient's welfare as the sole scientific approval required.

The psychologist's obligations are those set out in the European Charter of Professional Ethics for Psychologists, national codes of ethics and European regulations on medical and biomedical research.

### 3. Training

Certain universities offer courses on palliative care as part of initial training. They are not sufficient preparation, however, to practise the specialty. Specific training is needed that includes a common core of knowledge and set of values established in collaboration with healthcare professionals to promote future teamwork. Students in psychology should be encouraged to take a university diploma in the specialty. Some diplomas focus more on the human sciences and perhaps provide a broader view and include an internship in palliative care with a psychologist. There exist other training options and means of acquiring the appropriate competencies and experience such as lectures, congresses, courses, and the discussion forums of the SFAP (French Society for Palliative Support and Care). Advice and assistance can be gained from belonging to a network of peer professionals. The psychologist keeps up to date with professional issues and can take part in the work of collegial bodies such as the FISP (International French Association for Palliative Care).

## B. Clinical practice

### I. Theoretical-practical bases of clinical practice (*How and why?*)

#### 1. What constitutes clinical practice for the psychologist?

The aim here is not to give an exhaustive definition of all aspects of clinical practice but to identify which common elements unite psychologists in a professional identity. For clinical physicians these elements would obviously be different. The psychologist's domain of investigation is the mind, its contents and production and the language that allows access to its working.

Clinical psychologists are chiefly concerned by mental dynamics and their method is centred on a particular attention to its various modes of expression. Clinical practice works by establishing links that could lead to a new understanding of a situation or experience.

It is conventionally said that the clinician's place is at the subject's bedside. The term "subject" emphasizes that the individual is not relegated to the position of a "patient" nor assimilated to a patient's symptoms, whether somatic or psychological. Beyond symptomatic manifestations, psychologists assume the permanent presence of a mental dynamics, in the form of the subject's potentiality and resources. They believe in these capacities even if they are not patent. Their task is to fully embrace the enigma of the sentient being without necessarily assigning a formal meaning to it or interpreting it. In their encounter, the psychologist has to harness the subjects' potentialities to allow them to find their own answers. Clinical practice is part of a

wider, unpredictable encounter involving a process of co-construction that emphasizes what is singular, unique and specific.

The clinical encounter provides patients with the opportunity to reflect on and subjectively take possession of their illness. The encounter is proposed and not prescribed. The interaction between psychologist and patient is the meeting of two subjective entities. Psychologists use a clinical frame of reference to develop their own counter-transference in resonance with the subject's distress. Intersubjectivity provides a means of access to resources and the leverage by which they can be reinvested.

## 2. Therapeutic aim

An interview with a psychologist is generally expected to alleviate suffering and to restore balance by eliminating anxieties such as the fear of death or castration. Anxiety confronts the subject with the experience of ill-being and feelings of oppression, powerlessness and great vulnerability. In an end-of-life context the expectation can for a short time be experienced as pleasant, when the establishment of a relationship has a relaxing effect. However, anxiety plays an important role and is the sign of the intrapsychic conflict with the reality of death. It signals the existence of danger, which may be the reason why the interview was requested, to allow subjects to achieve a representation of loss and to reconstruct their defences.

What does "therapeutic" signify in palliative care? The word comes from the Greek *theraps*, which means the attendant or second of a combatant or competitor. In this sense, psychologists could be those who assist patients in zones of shared distress. Rather than soothing by their presence, they act as a support and create a space in which experiences can be shared. The aim of therapeutic interviews is to assist patients so that they have the mental strength to come to terms with a terminal illness. The challenge is to offer an alternative to the survival mechanisms that banish the experience of hopelessness from conscious awareness. The objective is not to eliminate feelings such as sorrow or loss but to support subjects in their ability to endure them, to temporarily control feelings of panic, to understand them or to integrate them into a psychic structure. The therapeutical function of the interview is not to do away with distress, even though this may be what patients desire, but to enhance the patient's ability to bear the suffering and live with it more easily.

## 4. The clinician's stance

For a long time it was thought that the role of the psychologist was to prepare patients who were largely in denial of the reality of their diagnosis or prognosis. The underlying aim was to work together to build an understanding of the illness so that the patients could have an intense and rational end-of-life experience. Although this idealized model has fortunately been renounced by psychologists it still has a great influence on families, who feel disappointed and guilty when they are unable to maintain a close relationship with the relative until the last moments of life. Professionals sometimes assign themselves in the closing stages of life the role of guide to the untutored, aided in that by some supposed knowledge based on their

repeated experiences with the process of dying. Psychologists can fall prey to this shortcoming when they take on the function of a “counsellor”. The role of the psychologist in palliative care is not to be a holder of knowledge but to conduct interviews within the supporting framework of active listening and free association that potentially have a therapeutic purpose. To fulfil this role, the clinician must combine several qualities.

- an internal aptitude for listening to and being available for the other person
- varied and specific conceptual references that lead to an understanding of body and verbal language and allow the psychologist to interpret and reformulate with confidence and ease
- the ability to adapt one’s language to the subject interviewed
- an attentiveness to questioning about the “here and now”

The clinician creates a therapeutic space without any planned expectations. The patient is received with empathy and without preconceived notions, and any previous knowledge the psychologist may have about the patient’s history and illness is put to one side so as not to raise expectations too high of the therapeutic effect. Empathy helps to establish a therapeutic relationship that is in harmony with the subject.

## 5. Therapeutic framework

The basic characteristics of the framework are verbal expression, free association and the primacy of imagination and fantasy.

The framework is the holding structure of the interview and is shared by patients and psychologists alike. By establishing a consistent ritual based on psychological theory it draws a line with external reality and heightens the attention given to internal tensions. The therapeutic framework remains an invariant.

Psychologists formulate hypotheses and present their interpretations to the patient within the limits of what they consider the patient able to understand or accept: they carefully handle suppressed feelings or experiences of splitting and defence processes. Their respect for the patient’s identity derives from their empathetic stance. Their words have a relieving and reassuring effect, reinstate the feeling of the continuity of existence, and are able to verbalize the previously inexpressible notion of dying.

## 6. Managing the clinical encounter

The way in which the framework is managed depends on the material arrangements put in place by the psychologist, which can be modified according to circumstances, planned or unforeseen. The clinical encounter is governed by such considerations as work tempo and time and space available. In a palliative care setting, it can be affected by constraints such as patient fatigue, interruptions by caregivers and institutional regulations.

To ensure that the clinical encounter is respected, psychologists should be flexible and adaptable in their collaboration with all the actors they work with. By prior

explanation intrusions can be avoided and interference reduced. In the patient's home, they can allow themselves to close doors, explaining the need to be in a quiet environment. They lay down the material conditions required for the proper accomplishment of their intervention. This respectful attitude shows the consideration they give to the patient's efforts to participate fully in the interviews. If they are not at all times concentrated this can have a mirror effect and patients may feel the encounter is irrelevant or inadequate to their situation.

Interviews are arranged either face to face or with the psychologist seated on one side. Face-to-face interviews allow the subjects to see and to be seen and render body language observable. They have the advantage of placing the psychologist in the subject's visual range, thereby strengthening the mirror effect of the relationship. The subject can sometimes experience the need for physical contact, to have the regressive reassurance of touch. For psychologists, the face-to-face encounter demands careful attention to their own body language.

At the end of the interview, the participants decide together on what happens next. For example, do the patients or relatives, or both, wish to arrange further interviews? When an interview is made for a patient, there is a projection forward in time that takes into account future perspectives such as the length of time between meetings, which is full of uncertainties. The psychologist is committed to the relationship in the present but with the paradoxical awareness that there is no guarantee that it will continue. Follow-ups can be ended at any time but are usually halted by death or finally interrupted a few days before. Some psychologists offer to stay by the side of patients who are in the last stages of life. Their presence is a means of respecting appointments made, a sign that accompanying the patient is still important and that another form of relationship is possible. Remaining present symbolizes the continuity of the relationship and lends support to the relatives and team members. The psychologist no longer undertakes interviews and their role is simply that of a human presence.

### 7. Afterwardsness (*l'après-coup*)

Psychotherapeutic practice involves two temporalities, that of the here and now and that of afterwardsness. Once death has occurred, psychologists reflect back on their impressions and lived experience of the relationship and draw up questions about their attitudes and how transference was resolved. It is a process of recall in which they attempt to give a meaningful shape to the contents of the interviews. In this way they throw a bridge between their raw material and their theoretical knowledge.

This difficult exercise can be made easier by the act of writing, such as the submission of reports to be included in the patient's record. Psychologists can be assisted in this work by individual or collective supervision (see section on Necessary conditions).

These basic practices are not peculiar to palliative care teams but are revisited here in the light of end-of-life treatment.

## II. Therapeutic orientations and tools

### 1. Theoretical orientations

Clinical interventions can be inspired by support psychotherapy, insight-oriented or life story therapies, or by the psychoanalytic model. The therapeutic aim of support psychotherapies is to strengthen the defensive and adaptive functions of the ego and to respect the psychoneurotic defences and the symptoms that protect patients against psychological disarray. Psychologists take on the role of an auxiliary ego when patient defences have collapsed. Their position is one of support.

Introspection therapies and *insight-oriented therapies are intended for less vulnerable patients whose ego functions are intact*. Their aim is to lead subjects to an awareness of their difficulties via the emotional experience of the interview and of their overall situation. Life story therapies attempt to restore the feeling of continuity that has been broken by illness. Psychologists assist patients in understanding their reactions to their illness by helping them discover a pattern in their life trajectory. This helps patients to discern a meaning where before they experienced only disorder and incomprehension.

Psychoanalysis is interested more particularly in the notion of transference and counter-transference and in the psychodynamic functioning of subjects between drives and defence.

Aside from the orientation chosen the effects of the psychotherapy depend on the robust theoretical grounding of the psychologist. During interviews, psychologists act as a receptacle in which patients are held and contained and that sends them back an echo. They are attentive to their own feelings so as to offer the best support to patients in their progression. Patients' life experiences can be seen as enlightening. The therapeutic relationship controls patients' distress and helps them in the struggle between what is perceived and what is felt to allow reality to be experienced and integrated into the ego. Interviews enable subjects to adopt a different stance when faced with the crisis of dying.

### 2. Some mediation tools

Clinical psychologists can be trained in different techniques such as sophrology, relaxation, psychodrama and Ericksonian hypnosis, which they may use during interviews. They can initiate work on the relations between the mental and the physical starting from bodily perceptions. Well-tried techniques such as hypnosis are used to treat certain forms of pain.

The psychologist can use various aids such as genograms, the Photolanguage method, and drawing to create a space in which sharing can take place. Drawing can represent what is not able to be articulated verbally. Genograms and the Photolanguage method both use visual aids that relate to personal identity or identity within the family. These aids allow the joint creation of an object along the lines of Winnicott's experiments with the squiggle<sup>2</sup>. Activities can also be initiated by the patients themselves.

The purpose of these tools is to facilitate the relationship, encourage expression and verbal articulation, and to contain emotion. They do not simply provide a response to symptoms but can in turn have a therapeutic aim or an application in clinical investigation or be used as a simple means of communication, their function changing from one encounter to another.

The psychologist observes how the patients take possession of the object to make it their own and the qualitative changes in the process.

### III. Subjects met with (*Who for?*)

#### 1. Mental problems

The main concern of all situations is the illness, in its serious, progressive or terminal phases. Being diagnosed with a serious illness can abruptly change the individual's representation of self: the healthy subject becomes a patient in need of care. The medical verdict, even when announced in a context of support, can cause a fracture which for the subject designates a life before and after the disruptive event.

The realisation that one's own body is under threat of death can be experienced as a trauma. The individual's mental life is affected by injury to the body, identity crises and the specific distress of facing death. Life-threatening conditions, the notion that one's time is "running out" and losses related to serious illness are assaults on the subject's psychic integrity and a challenge to their continuing existence.

The psychologist intervenes at a time of separation, loss, bereavement and the fear of death, of one's own or that of the other. In such a period, the usual mechanisms of defence can be stronger and sometimes more rigid.

#### 2. Indications for intervention

Distress is one of the main reasons for referral to a psychologist.

Psychologists are often called upon to see subjects contending with the reality of their illness, which can manifest itself some time after diagnosis has been made. They can also intervene for other problems, at work or in the family for example, that are related to serious illness.

The care teams can indicate to the psychologist which patients are in difficulty. Subsequent interventions must be analysed to distinguish between discussions with the team and patient requests for a meeting.

Psychologists' qualifications do not give them priority in handling urgent psychiatric cases, which firstly require the intervention of a physician. They can give an opinion on the feasibility of certain projects by representing the wishes of the patients and their relatives. Their role is not to influence patients to accept a medical decision concerning treatment, surgery or hospital discharge.

They decline to become involved if they think that their intervention would be inappropriate. They could consider, for example, that in certain cases family functioning is incompatible with conducting several parallel follow-ups, which could harm their stance of benevolent neutrality. They would refrain from simultaneously

following patients and their relatives or friends if they thought that this would lead to interference and bias.

At the same time, psychologists make themselves available for formal or informal discussions with the team of caregivers. They provide specific details about the life experiences of the patients and relatives in their care. They help the caregivers to avoid conflict with the patient's defence mechanisms by teaching them to respect the strategies of denial, projection and displacement and to encourage more evolved or elaborated mechanisms such as humour and sublimation.

### 3. The question of the subject's request and consent

Psychologists make sure that the subject is aware of their professional status before conducting an interview. They can choose to spontaneously introduce themselves to patients without receiving a formal request for a meeting. The patient's consent is always required, however, for any intervention. When patients are unable to give consent verbally or in an informed manner, the psychologist must nevertheless make sure that they are in agreement with what is proposed.

Psychologists endeavour to analyse the patient's request to better adapt their intervention, which is constantly evolving, in response to the reality of the illness and other factors such as the patient's environment.

Caregivers or relatives can sometimes identify a need for psychological support that is at odds with the patient's own feelings or perceptions. If a patient declines support the psychologist accepts and reflects on the decision while helping the team to cope with their frustration. Discussions are also held with the team on how to present and explain the psychologist's function, what to say about it, at what moment, and who to. Psychologists inform the team about the effects of a proposed intervention, which can be experienced as stigmatizing, as an admission of failure or a sign of weakness or mental disturbance. It can also arouse feelings of anxiety or even guilt, when for example relatives feel that time spent at an interview means less time spent with the ill person or when they judge that they should not allow themselves to think about their own preoccupations or welfare. In these cases, the psychologist's role is to reassure the caregivers and relieve the tension.

## IV. Various forms of encounter

As a general rule, the psychologist meets patients and their relatives individually. The meeting can, however, be organized in various ways, not necessarily at the request of the psychologist but according to circumstances.

The psychologist ensures that subjects are received in conditions that respect their privacy, safety and comfort and the stability of the working framework. The encounters can evolve but whatever form they take and at whatever pace they proceed they retain meaning and value. Each encounter is different and has its own dynamics.

## 1. Informal encounters

The psychologist avoids a simple encounter outside of the work place and working hours from becoming a proper interview.

In the professional framework, an informal encounter differs from an interview in various ways: there is no request by the subject for a therapeutic intervention, time is limited and there is no dedicated place of exchange.

The encounter can take place at a location shared with professionals other than psychologists and hence is unscheduled and more spontaneous.

Meeting the psychologist in a flexible environment gives subjects insights into certain aspects of the profession and allows them to begin building a relationship, to register certain anxieties and questions and to address certain messages.

The psychologist should make efforts to remain at the subject's disposal even when the material circumstances are potentially destabilizing. In the event of extreme occurrences such as death, physical complications and the disclosure of prognosis the psychologist, by being present, declares a commitment to the subject, relatives and care team, even at a moment when an interview is neither possible nor requested.

## 2. Multidisciplinary interviews in pairs

The multidisciplinary approach in palliative care includes interviewing in pairs. The psychologist is not used to this practice, which requires proper training and mutual acknowledgement of each colleague's skills and theoretical references. The interviews can be carried out by a physician and a psychologist or by a paramedic and a psychologist, at bedside (either in the hospital or at the patient's home) or in a more formal setting such as an office.

Two modes of action are possible.

- A presentation interview. This is proposed when patients have not formally requested psychological support (whereas the care team is persuaded of the need) or if they are apprehensive about meeting a psychologist. Being accompanied by a health professional whom you already know is potentially reassuring. This first encounter can be the gateway to a course of individual care.
- A support interview. The psychologist can be present with a health professional when an important decision is announced that may subsequently affect relations with the patient. In a multidisciplinary setting, interviews in pairs help all health care providers to better assess the psychological challenges engendered by the serious illness.

## 3. Support for relatives and friends

Individual or group support can be provided.

- Group support consists in assembling several of the patient's relatives with the aim of creating a space for dialogue in which the defences and temporality of all involved are respected. These group encounters are sometimes called "family meetings". They are not the occasion to say or hear all that can be said or heard but to create

the opportunity to communicate what is ready to be understood. This type of meeting can be occasional, the first in a series, or lead to other kinds of encounters. Whatever form they take, the patient, if taking part, is consulted to give consent. If the patient does not request an interview but one is asked for by relatives for themselves, the psychologist decides whether it is opportune to inform the patient about their existence. In an institutional setting, it is important to take into account the circulation of information, to avoid creating a secret that could be harmful to everybody, and at all times to protect the confidentiality of the contents of the interviews.

- When one member of a couple is suffering from a serious illness, the psychologist can conduct what is called a couples interview or a couple-focused interview to examine the repercussions of the illness on their relationship. Other couples among the patient's relatives could also be granted interviews, which would be considered, however, as family interviews since they relate to the illness as experienced in the family context.
- The psychologist can also propose interviews to a friend or close acquaintance of the patient, after assessing the extent and importance of the ties between the two and with the family. When several requests for individual interviews are made by members of the same family, the psychologist gives priority to one only and refers the others to colleagues outside the department.

#### 4. Support groups with relatives and friends or patients

These groups allow those confronted with serious illness, whether patients themselves, their relatives or friends, to meet other people who are undergoing the same ordeals of bereavement, illness or seeing a loved one suffer. The meetings allow each one to put into words the pain they are experiencing and to share with others the difficulties they encounter and also to find mutual support and sympathy. Respect for all persons and for their confidentiality is an essential requirement for these meetings. Discussion groups most often convene in an institutional setting, in the palliative care unit, for example, but do not exist on a wide scale. They are difficult to manage, owing to the varied problems and expectations of the participants, the interweaving of affects and representations and the need to conjoin the group's dynamics with the psychic dynamics of the subjects. The psychologist, sometimes in tandem with a colleague, ensures there is compatibility between the group and the psychic balance of each individual.

#### V. Institutional and team support (*Who for?*)

Psychologists devote part of their activity to interventions at an institutional level in collaboration with other professionals such as occupational psychologists, health executives and department heads. These interventions are an integral part of their remit for two main reasons.

- The organization and past history of the institution have an active influence on the care and management of patients and relatives.
  - Patients' problems can cause difficulties for the institution and professionals.
- Their institutional role does not only concern the institution that employs them but in a wider context the authorities on which the institution depends. These interventions complement their clinical work schedule and may involve travelling.

### 1. Institutional work groups

By virtue of their professional status, psychologists in palliative care can be called upon to take part in different work groups. The topics dealt with do not always fall within the field of psychology and require an effort of adaptation with regard to common knowledge and terminology. The psychologist's role is to defend the psychic dimension of the subject and to provide insights into the specific characteristics inherent to the practice of palliative care such as intersubjectivity and the notions of uncertainty and vulnerability.

Work groups can be local, regional, national and international and can operate across and within institutions, like ethical research committees, for example.

### 2. Discussion groups

Different terms have been suggested to designate this type of group. From a pragmatic point of view, it was decided to choose "discussion group" as bringing together what are variously called, depending on the setting, thematic working groups, debriefing and supervision groups, and groups for analysis of the institution and professional practice.

In discussion groups, psychologists encounter diverse professionals involved in patient care such as caregivers, teachers, specialized educators, home-help workers, medical and allied health personnel and other psychologists. The psychologist's services are often proposed to health care professionals faced with complex situations of patient care and management that require significant personal commitment.

According to the past experience of the teams, how they are structured, the relationships between the members and their expectations, the psychologist defines how information is communicated, who should attend meetings, where they should be held, and what time limits should be set.

Discussion groups can be either open or closed, more or less regular and of varying duration. Whatever their framework, it should be clearly defined and understood by all those taking part. The presence of the psychologist serves as an anchoring point, ensuring that all participants can express themselves freely and that the topics dealt with are fully exposed. The psychologist guarantees a non-judgemental appraisal of those attending or absent from the meetings and fosters a climate of goodwill while insisting that what is expressed by individuals should not be divulged outside the group, in contrast to collective statements, which can subsequently be communicated to the team. Discussion groups differ from meetings in which information is imparted. The psychologist is there to allow feelings and experiences to be expressed but cannot remedy all instances of suffering in the workplace. When required to deal with

an emergency, the psychologist is aware that a longer term commitment might be required. **ne fait pas l'économie d'un travail à distance/ dans l'après-coup.???**

Palliative care groups have several specific characteristics.

- In palliative care teams, discussion groups are considered an integral requirement for care and meet regularly. Caregivers attend on a voluntary basis.
- The groups can be led in tandem with other members of the team such as physicians and nurses. As physical illness is the crux of the situation, a physician deals with all matters specific to medical care. Physicians, by virtue of their peer status, also help establish a relationship of trust with the health care teams. It is easier to contain the phenomena of transference in the groups and to have a more robust management of the participants' projections when there are several people working together. Group leaders must adopt a particular stance to register feelings of guilt, anxiety, helplessness and anger. Their aim is not to give the team training in knowledge of palliative care treatment. Their stance requires humility, the ability to listen and a measure of modesty. It is frustrating not to be able to call upon one's knowledge in reply to questions under discussion. Working in tandem requires adjustments to one's attitudes and, of course, mutual respect. Without these, the pair would not be able to offer containment to the group. Setting aside time for preparation and analysis would also help the pair to make progress.
- Temporality in palliative care is of a particular nature and hence requests from patients and families can be pressing and singular in nature and expressed with great intensity. What occurs within the group is complex and releases strong emotions. The groups serve as debriefing sessions. A traumatic event that threatens the individual's or the group's equilibrium elicits spoken reactions from which the course of patient management over time (treatment, care, decisions, medical disclosures) is recreated. The group provides insight by recognizing and understanding the difficulties it is experiencing in relationships with the patients, which in turn leads to a new attitude. Collective knowledge is created from which meaning may emerge.
- Discussion groups can be formed on request during or after follow-up. They can be convened after a patient has died, when the circumstances of death were traumatic or when the number and rate of deaths overstretch the teams' mental and physical resources.
- The psychologist can lead a group to discuss a patient or family being seen for therapy. In this case, the psychologist must be able to listen to and understand the problems that are affecting the group. The natural curiosity of the team members should not lead the psychologist to betray the confidentiality of the interviews with the patient or relatives. The psychologist must withdraw from the transference relationship with the patient or family so as to refocus on the group and what it has to say. Should these conditions not be met, another therapist should be contacted to intervene.

### 3. Training/awareness programmes

Training and awareness programmes play an integral part in the organisation of palliative care. Psychologists can conduct training courses in this field aimed at the general public and caregivers alike. They can give courses to health assistants and in nursing and medical schools.

This particular activity can figure in the job description and be an employer's requirement for the position. Being a trainer calls upon skills other than those needed for clinical practice. These skills are acquired either through experience or by specific training courses that develop good pedagogical practice. Course content must be grounded in the humanities and have scientific value. Psychologists should exercise this activity in accordance with their principles and values, and with the ethos that guides their clinical practice.

## PROSPECTS

This frame of reference should be considered as a work basis that gives a clear and simple presentation of the common international practice of psychologists working in the field of palliative care. Its major interest is to provide some general points of reference for what is a complex exercise. It creates the opportunity to open up a dialogue and offers a source of reflection on how to undertake the psychologist's practice.

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- Organising the annual national conference

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- Keeping abreast of developments in society
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