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## **A booklet for Psychologists in Palliative Care for Evaluating Distress and Identity Crisis**

A. van Lander, Raymond Hermet, Bruno Pereira, Céline Deveuve-Murol,  
Claire Valour, Jacques Gaucher

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Van Lander Axelle<sup>1,2,3</sup>, Hermet Raymond<sup>2</sup>, Pereira Bruno<sup>4</sup>, Deveuve-Murol Céline<sup>5</sup>, Valour Claire<sup>6</sup>, Gaucher Jacques<sup>1</sup>.

<sup>1</sup>Laboratory EAM-SIS 4129, University Lumiere, F-69500 Bron, France ; <sup>2</sup>CHU Clermont-Ferrand, Center of palliative care, F-63003 Clermont-Ferrand, France ; <sup>3</sup>Reseau Palliadam, 63000 Clermont-Ferrand, France ; <sup>4</sup>CHU Clermont-Ferrand, DRCl, F-63003 Clermont-Ferrand, France; <sup>5</sup> Hospital, F-63220 Riom ; <sup>6</sup>Hospital-Emile Roux, F-43 000 Le Puy-en-Velay, France.

\*from the resaerch work by Van Lander A for a PhD in psychology.

Contact: avanlander@chu-clermontferrand.fr

## MAIN OBJECTIVE

Study the distress of patients followed up in palliatif care (PC). This quantitative and qualitative studies verifies the relevance of a form which is designed to capture and quantify the links of this distress with an identity crisis generated by the lethal disease.

### Hypothesis

Links between the patient's distress and fatal illness can be evaluated through the perceptions of their psychologists.

### Originality

Create an instrument for collecting representations of Psychologists relationship to the patient in this three-way interaction where the protagonist is the lethal disease.

## GEOGRAPHICAL SCOPE

All psychologists of palliative care, in one French region, Auvergne, took part in this research in 2010. 4.716 patients followed up in PC.

Demographic profile of Auvergne, the same as 88 European regions :

Burgundy, 2 Spanish regions, Asturias and Extremadura, 2 Portuguese regions Centro and Alentejo, the vast majority of German, Romanian, Bulgarian and Baltic regions and a handful of Scandinavian regions.



## METHODOLOGY

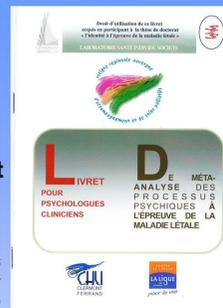
### 1. Creation of a form and a booklet

Used with 23 patient and than created, it is a grid of concepts to collect representations :

- of the psychologist patient's mental processes ;
- its own cons-transfer ;
- maintenance functions.

The psychologist open a booklet and then filled out a form after each patient interview. It does not change their practices.

*This booklet is a manual of instruction and definitions of different psychological concepts necessary to analyze intersubjective relationship*



Form:

### The patient's psychic functioning :

- Intensity of the loss caused by illness
- Distress thermometer (DT)
- Rupture identity<sup>3</sup> or new component
- Defense mechanisms

### 2. Items

- Choice of 35 items of psychology concepts highlighted in the literature on distress and crisis of identity in palliative care.

Theme: intersubjectivity.

*"The suffering associated with lessening implies recognition of fluctuating psychological partners"* (Ruszniewski M, 1995).

### 3. Principal measuring tools

- A qualitative ordinal board for losses caused by illness,
- Visual analogic scales (VAS) for 23 concepts,
- A qualitative categorical board for breaks identity,

- The Clinical Global Impression (CGI-3) to evaluate the therapeutic effect,
- Free notes.

### 4. Coverage

Psychological interviews.

### 5. 14 psychologists included

- With clinical activity for patients
- With differents exercises to overcome the individual peculiarities.

### 6. 100 patients

Psychologists evaluate their representations of their interviews with patients.

## RESULTS

284 forms

First interviews realized 37 days in average before death and last 17 days before it. One interview per 7,4 days. Usually 3 interviews per patient. Illness appeared in average 18,7 months before.

**PATIENTS**  
55 men, 45 women.  
Middle age: 69 (33-91).  
23% at home,  
62% at hospital,  
15% department of PC.

**PSYCHOLOGISTS**  
1 men, 13 women.  
Middle age: 33 (26-45).  
12 Teams: at Home (4),  
at the hospital (7),  
at the PC department (1).

Results show that the form is relevance to evaluate the distress:

### 1. Validity

- All forms are filled and the items used which shows a good adaptation to the representations of psychologists and therefore its **acceptability**.
- The correlation analysis and ACP shows that the selected concepts are linked with distress ( $p < 0.05$ ).

### 2. Sensitivity

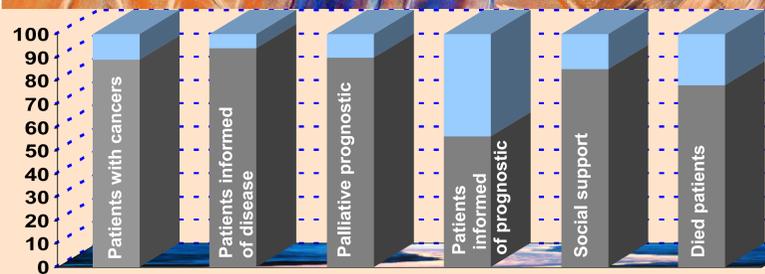
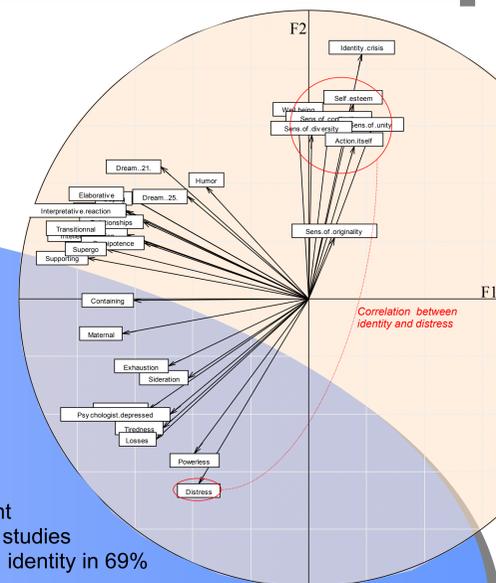
- It is very sensitive regarding the study. It identifies the distress in 88% of interviews. This is considered significant in 53% of the interviews that is usually higher than the results reported by studies in palliative care (between 30 and 42%). It also helps identify the failures identity in 69% of interviews.
- The EVA and the two tables seem appropriate to the phenomena measured. They allow a balanced distribution of results.
- It detects differences in the same patient between interviews. The fifth interview mark significant differences: distress( $p=0.03$ ), identity crisis( $p=0.02$ ), thoughtful( $p=0.01$ ), interpretive( $p=0.01$ ). The ability of patients to dream increased significantly in all visits !
- It noted the results sufficiently differentiated between patients (losses, distress and crisis of identity: between patients variability > 40%).
- It mesures significant correlations between cons-transfers and distress: helplessness ( $p < 0.001$ ), sideration  $p=0.004$ ), exhausting( $p=0.007$ ) and depressive( $p < 0.001$ ).

### 3. Fidelity

- The different parts are homogeneous with a good inter-item consistency (Cronbach  $\alpha > 0.70$ ).
- Assessments of psychologists are similar for distress (between psychologists variability 15%) but divergent for identity (variability 40%).  
→ subjectivity should be considered for this item in the study.
- Good temporal stability between 2nd and 4th interview.

## PROSPECTS

1. Study of 237 booklets, used in 2010 to understand the links between distress, identity crisis and lethal disease.
2. In 2011: a second group with the National College of psychologists SFAP is involved. This Study will finish in 2012...



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