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Psychological aspects of shared decision-making at the end of life: creation of an observation tool

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Abstract

Background

There are currently no tools available for observing the psychological processes that guide shared decision-making at the end of life.

Objectives

This article aims to formalize a methodological framework for the design of an exploratory scientific study based on participant observation by psychologists. The main objective of the tool is to enable the observation of the psychological distress of patients and the psychological experiences of all those involved in shared medical decision-making (patients, relatives, professionals) during the end-of-life decision-making process.

Methods

An observation tool for psychologists in palliative care was developed through an integrative methodology based on a structured review of the literature. A preliminary version of the observation tool was submitted to 11 expert psychologists practicing in end-of-life care, via the Delphi method. Quantitative and qualitative analyses of the comments and content of individual and group interviews were conducted. Statistical analysis focused on measures of central tendency, dispersion, and distribution.

Results

The final version of the observation tool comprises 57 items. The tool was applied in 54 palliative care cases; 44 complete data sets were obtained. Statistical analysis demonstrates good acceptability, feasibility, and reliability of the tool.

Conclusion

The tool enables psychologists to observe shared decision-making by focusing on the psychological determinants of the process. Without any psychometric ambitions, the observation tool is designed to facilitate participant observation in a psychological context and adequately fulfils the objectives for which it was developed.

BACKGROUND

Patients at the end-of-life-decision (EOL) face difficult decisions. The palliative approach advocates shared decision-making (SDM) (1–6), based on the unique experience of each participant involved. Since the 1990s, various studies have described the benefits of shared making-decision (SDM). This proactive, patient-centered approach involves family members. It is based on sharing information and taking patients' preferences into account (7–9). SDM in palliative care takes place in a context marked by great uncertainty, high emotional intensity, and complex medical decisions (e.g., starting or stopping treatment, symptom management, or place of care) (6). Patients and their families often feel that they do not have a real choice, which complicates engagement. Qualitative studies highlight the non-linear and evolving nature of SDM, which is influenced by the timing and type of decision, interpersonal dynamics, and institutional constraints (1). While the physician-patient duo remains central, nurses and informal caregivers often play an essential, albeit underestimated, role in facilitating the process. Key components of SDM in this context include awareness of choice, clear presentation of treatment options, two-way exchange of information, mutual agreement, recognition of expertise, temporal and systemic considerations. It should be noted that emotional and systemic dimensions remain underrepresented in many theoretical models. This framework positions SDM as a contextual, relational, and iterative process that must adapt to the realities of palliative care practice.

While current paradigms often conceptualize decision-making as an essentially rational process, numerous studies have demonstrated the important role of subjective and emotional factors (10, 11, 6, 1). Psychological components involving reciprocal influences between patients, families, and healthcare professionals shape the decision-making process (12). In palliative care, EOL situations frequently elicit emotional distress – not only in patients but also in caregivers and clinicians – which can alter perceptions, preferences and the ability to engage in shared decision-making. Although SDM is widely encouraged in palliative care, most theoretical models significantly underrepresent affective dimensions (1, 6). Emotional states such as distress (12–14), can significantly influence the dynamics and outcomes of the decision-making process. The proximity of death highlights the difficulties of communication between the patient, their relatives, and healthcare professionals. When distress occurs, it becomes more difficult to make sense of events: the group's capacity for symbolization is sometimes overwhelmed. Decisions may then be more impulsive or based on defensive reactions. The subjective experiences of each of the actors involved in SDM can influence and guide the decision made. End-of-life decisions raise complex psychological issues. Studies have sought to understand and structure EOL decisions in order to alleviate psychological distress (15). Others have focused on the distress experienced by professionals (16), or have observed their emotional experiences when participating in EOL decisions (17). However, no study to date has specifically examined the relationship between SDM and patient distress in EOL. Furthermore, there are no relevant clinical data collection tools available to meet this research objective.

This study forms part of a broader research program (Psy2DéPall) that seeks to propose a methodological framework for exploring the relationship between SDM and emotional distress un patient at the EOL. The exploration is based on participant observation conducted by palliative care psychologists. This article aims to fill a gap identified in the literature by describing the design and

development of a specific structured tool for palliative care psychologists. The approach adopts a clinical and interpretative paradigm: rather than producing standardized scores, the observation tool is designed to encourage reflection on the emotional, cognitive and relational aspects of EOL decisions. It is intended for use as soon as the decision-making process arises and aims to inform –not measure- clinical reasoning.

Based on constructivist epistemology, the research recognizes clinical observation as a valid means of knowledge production, particularly in emotionally complex settings such as palliative care. The value of such a tool lies in its contextual relevance and its contribution to interdisciplinary and ethical reflection. The psychological indicators it allows to be observed, in the context of interpersonal relationship, are what make it so unique. The development process includes a literature review, expert consultation, field testing, and user feedback.

Psychologists who play a key role in French palliative care teams (18–21), will use this tool to capture intersubjective dynamics through non participant observation (22–25).

METHODS

This study comprised two complementary components: the development of a structured clinical observation tool and an expert review process aimed at assessing its conceptual relevance and practical applicability.

The observation tool was designed for systematic use by psychologists working in palliative care settings. It is intended to be implemented as soon as a decision-making process arises in the course of patient care. Data collection is based on participant observation, whereby the psychologist remains actively involved in the clinical context while maintaining a reflective and analytically informed stance toward the psychological and relational dynamics unfolding within the decision-making process.

The tool does not aim to evaluate patients or produce standardized measurements. Rather, it is conceived as a structured framework to support psychologists' clinical reasoning regarding the emotional, cognitive, and relational dimensions of EOL decisions. Its purpose is to enhance reflective practice and to facilitate interdisciplinary dialogue and ethical deliberation within care teams.

DEVELOPMENT OF A STRUCTURED OBSERVATION TOOL

An empirical research methodology was adopted. It was based on an integrative approach combining insights from multiple theoretical perspectives (e.g., cognitive, emotional, and psychoanalytic frameworks), enabling the development of a tool that reflects the theoretical diversity of the field and thereby offers a more comprehensive understanding of the complexity of the phenomena under study. This approach allows for a nuanced and multidimensional observation of the decision-making process and supports the operationalization of a tool aligned with the study's objectives.

A literature review was conducted using the following MeSH terms (January to August 2023): Decision Making, Shared Decision Making, Emotions, Cognition, Implicit Bias, and Psychological Experience. Topics unrelated to health, EOL and palliative care were excluded, as were those dealing with paediatric issues. In France, the Clayes-Leonetti Law marked a major turning point in EOL care by formalizing shared decision-making. To ensure compliance with this legal and ethical framework, the literature review was limited to articles published between February 2016 and October 2023. This decision ensured that the observation tool would reflected contemporary clinical realities and ethical standards in French palliative care. Titles and abstracts were screened according to the following inclusion criteria: measurement scales, psychological determinants, and psychological experiences. The objective of the literature review conducted in this study was not to perform a systematic synthesis, but rather to identify key psychological constructs and empirical findings that could inform the development of a clinically relevant observation tool. Although several databases were initially consulted (PsycINFO, PubMed, Google Scholar, and JSTOR), PsycINFO provided the most pertinent and comprehensive results. Given our applied aim and the conceptual saturation reached through this source, we considered it sufficient to support the categorization process required for the tool's construction. While this may limit the inclusion on earlier international literature, it strengthens the tool's contextual relevance and applicability in its intended national setting.

The approach in the development of this non-psychometric instrument was designed to facilitate the observation and documentation of psychological experiences during decision-making processes. The creation was based on the identification of psychological determinants relevant to the research topic, using a targeted review of the literature, drawing on recognised theoretical frameworks and translating them to observable dimensions: distress end psychological feelings, motivations, defence mechanisms and reasoning processes.

The items were scored on a 0 (not observed) to 10 (strongly present) scale with optional qualitative comments. Items were grouped into five conceptual dimensions (general date, cognitive aspects, emotional dynamics, psychologist's positioning) but the tool did not generate an overall score or quantitative profile. It purpose was not to assess or compare, but to structure clinical reflection. Aggregated scores were not used in clinical practice, though they were analysed statistically during tool development to assess consistency and clarity. Each visual analogue scales corresponded to a clinical domain identified as relevant based on both literature review and clinical experience.

The tool was implemented via digital platform (LimeSurvey) to facilitate a content revision and experts feedback. Use of tool was based on the clinical commitment of psychologists and their live clinical experience. Psychologists were able to use it in situations in which they were directly involved, or during multidisciplinary discussions where the decision-making process was discussed or anticipated. In all cases, psychologists adopted a participant observer position, combining clinical engagement with reflective observation. From September 2023 to January 2024, they were invited to use the tool based on real clinical cases, completing it shortly after the clinical encounter, allowing the psychologist to document observed dynamics without disrupting the care process.

No content validity index was used, as the aim was not psychometric generalizability but contextual fit within clinical palliative care settings.

EXPERT REVIEW PROCESS

In the absence of a reference framework or standard to provide a point of reference, an expert consensus was required to determine the validity of the new tool. A Delphi method was particularly well-suited for establishing content validity, item relevance, the comprehensiveness of the measured dimensions, and the overall clarity of the tool. A modified method was used to validate the tool's suitability for its intended purpose, while retaining the method's fundamental principles. The study employed a qualitative approach, focusing on the iterative analysis of expert feedback rather than a quantitative measure of consensus. The aim was to assess the scientific relevance, clinical applicability, and usability of the tool within routine palliative care psychology practice.

Experts

Psychologists working in adult palliative care were invited as experts, based on their daily experience with EOL decision-making. Recruitment occurred via national mailing list and professional events, such as the congress of the French Society for Palliative Care (SFAP) which brings together approximately 300 psychologists in a professional body. Participation was voluntary, anonymous and based on informed consent. The experts had to belong to the same disciplinary field, palliative care, for which a clinical practice guideline exists. Inclusion was open to all, regardless of experience level, training, or institution. The diversity of the evaluators' profiles ensured the relevance and applicability of the tool in different contexts. Information sessions were offered prior to the revision phase, specifically to prevent disagreements and ensure consensus on the toll's components (conceptual definition, glossary).

Two rounds were conducted, prioritizing qualitative content validation through expert clinical feedback, rather than seeking statistical consensus. The data were collected anonymously and confidentially over 9 weeks. Two versions of the observation tool were proposed to the experts (2 rounds), and each included sections for providing free-text comments.

Tool refinement

An initial phase of observing the tool in clinical practice allowed experts to conduct a critical analysis. A first exploratory cycle, based on open discussions, was carried out. The tool was then revised following the exchanges and shared with the experts via email. A second cycle of critical discussion was organized using the same procedure, with open and anonymous interviews. Experts were invited to freely comment on the clarity of each element, its clinical utility and its applicability to real-world decision-making situations. The method relied on structured, real-time notetaking. This approach was not intended to identify themes, develop a theory, or create a psychometric test, but rather to improve the

tool's structure. The feedback gathered during face-to-face and online discussions was not subjected to formal qualitative analysis. They were integrated iteratively: elements were reformulated, improved, or removed based on participants' clinical experience and discussions, to enhance clarity, relevance, and ease of use. This pragmatic approach aligned with the study's objective: to ensure the tool's integration into the routine practice of palliative care psychology.

During both rounds, participants spoked freely. Contentious points were addressed. They were able to suggest modifications until the interviews concluded, at which point data saturation was deemed insufficient. Methodological rigor was ensured in several respects: the objective of the interviews was stated from the outset, the participants' level of expertise was verified, comments and modifications were recorded, and all points raised were discussed and collectively validated. The decision-making process was thus based on their expertise and collective deliberation: conceptual difficulties, terminological inaccuracies, and semantic ambiguities sparked collective debate, fostering the emergence of arguments, and supporting a deliberating approach; the goal being the stabilization of the concept. To limit interpretation biases, the modifications were collectively validated at the end of each phase, seeking consensus: the absence of substantiated objections and the explicit agreement of the participants led to the immediate integration of the changes. Illustrative quotations demonstrate the relevance of the analysis and the transparency of the iterative process.

The group finally gave its explicit agreement to conclude the method in two rounds, based on a qualitative consensus established regarding the principles underlying the discussion.

The final version (Appendix 1) was then developed using qualitative input and descriptive statistics (means, medians, quartiles).

In addition to qualitative analysis and descriptive statistics, an exploratory Principal Component Analysis (PCA) was performed to examine the internal organization of the main dimensions captured by the observation tool. The PCA was not intended for psychometric validation but rather to provide a visual representation of the relationships between key psychological indicators and to explore the conceptual coherence of the instrument. The quantitative variables included in the PCA corresponded to the mean scores assigned by psychologists when completing the tool in clinical practice. The following aggregated dimensions were considered: hetero-evaluated psychological distress, defence mechanisms and motivational profiles. PCA was conducted on the correlation matrix of these variables, and results were visualized using a two-dimensional factor map. Given the limited sample size relative to the exploratory nature of the analysis, the PCA results were interpreted descriptively and used only to illustrate potential relationships and conceptual proximities between the key dimensions of the instrument.

Boxplots were generated for the motivation and defence mechanism scores to visually represent the distribution of responses, including medians, quartiles, means, and individual values. These graphical representations were used to explore the variability and the dispersion of responses across observations.

The experts' participation was subject to their content. They had the option to leave the research freely. All date was anonymized during the research process. The Delphi modified process was conducted and reported in accordance with the Conduction and Reporting Delphi Studies (CREDES) recommendations. The study was approved by the Clinical Research Ethics Committee of the Centre Hospitalier de Valenciennes on October 5, 2023 (reference CHV-2023-012).

RESULTS

CREATION OF THE OBSERVATION TOOL

Of the 123 articles identified in PsycINFO, 45 met the inclusion criteria after title and abstract screening, followed by full-text review when necessary (Fig. 1). These were complemented by academic literature (books, doctoral theses…). It informed the drafting of the observation tool with a focus on the social, emotional, and cognitive dimensions of decision-making processes. The observation tool was developed according to a literature review and included 76 questions, grouped into five sections, presented in a computerized version (LimeSurvey) (Fig. 2). Section 1 corresponded to general data (9 questions addressing, for an example, age, gender, hospitalization locations along with a free-text comment section). Focuses primarily on the specific criteria at the heart of the research objective (4 sections). Thirty questions focused on the decision-making process, eighteen on cognitive components, fifteen on emotional components, and four on the role and positioning of the psychologist.

Each component was rated using a 0–10 rating scale, reflecting the degree to which the component was observed in the session (with "Not rated" as an available option). Optional comment boxes allowed for contextual or qualitative annotations to be added to support interpretation of the observed processes.

Emotional assessment

Emotional experience is assessed through:

- -A hetero-evaluated distress score for the patient, based on the Distress Thermometer, a tool validated in the French clinical context by psychologists. A score ≥ 3 is considered clinically significant (26).
- -A composite affective scores for other actors (relatives, caregivers), built on a structured synthesis of existing literature, measuring the presence of indicators such as anxiety, guilt, projective identification, or ethical tensions.

Motivation assessment

Drawing from specific decisional challenges encountered in palliative care, three motivational scales were developed to explore the frequency and nature of arguments mobilized during discussions:

- -psychosocial motivations: references to well-being affective, psychological or existential needs;
- -somatic motivations: references to physical complaints or bodily symptoms;
- -regulatory motivations: references to legal norms, institutional rules, or protocols.

Defence mechanisms

These scales aim to capture how individuals manage internal emotional conflicts. The defence mechanisms are categorized according to their level of maturity (27), in 3 main groups:

- -matures defences (e.g., humour, anticipation): flexible and adaptive strategies that support social and personal integration.
- -intermediate or neurotic defences (e.g., repression, displacement): less flexible but still functional coping mechanisms.
- -immature defences (e.g., denial, idealization, projective identification): rigid, often maladaptive mechanisms that may hinder constructive engagement with reality.

Decision-making logics

Two distinct decision-making styles were included to account for how decisions are processed:

- -an analytical logic: slow, deliberate, and rational;
- -an intuitive logic: fast, automatic, and closer to clinical intuition.

CONTENT REVIEW

Forty-four French psychologists working in adult palliative care were invited as experts. Twelve psychologists were initially involved: one did not confirm their participation, one withdrew during the review phase, deemed too involved in the tool's creation to guarantee objectivity, and one informed us of their departure, declining to participate in the critical review. This means that 25% of the psychologists initially hired did not go as far as the final content review phase.

Eleven psychologists provided their consent to participate in the study by completing a form for data collection. The psychologists were women, with an average age of 38.5 years, and had been practising for an average of 15 years, including 12.5 years in the field of palliative medicine. They worked in a various palliative care setting (Fig. 3). They came from different departments of France: 3 from Gironde, 3 from Finistère, 1 from Savoie, 1 from Nord, 1 from Pas de Calais, 1 from Puy de Dôme, and 1 from Charentes-Maritimes. Twenty-seven percent of participants had received additional training in palliative care, and 27% had received additional training in ethics. Information meetings were held via videoconference individually (n = 6), in groups (n = 4), or face to face (n = 1). The participants were instructed to use the observation tool systematically for all decision-making situations. Fifty-four cases

were included. Two psychologists were unable to include any cases, and one withdrew from the research.

Analyses of the 44 complete datasets were conducted.

Delphi Round 1, Round 2 and data integration

A first version of the observation tool was presented during individual or group videoconference sessions (n = 6 individual, n = 4 group, n = 1 in-person) between September 2023 and November 2023. Psychologists tested the tool in real clinical settings and shared oral feedback during group discussions, focusing on its clarity and clinical relevance. Two participants were unable to identify relevant decision-making situations during the study period; one withdrew from the process.

The revised tool was resubmitted to the same participants for a second round of review in January 2024.

Analysis of the verbatim data from individual (n = 4) and group (n = 2) interviews with psychologists added further insight into the feasibility of the observation tool. The psychologists described the first draft as “overloaded and tedious” (id1) and noted the “overall difficulty in managing the time it requires” (id1), which accounted for their “difficulty in including” (id4,5,2). However, the psychologists agreed about the value of the tool, stating that “the more you use it, the simpler it becomes”. The nuances of some concepts, such as “decision-making processes”, “decision-making issues”, “preferences” and “companionship”, were reported to be difficult to understand. The concept of “distress” was also deemed too intense to assess the feelings of loved ones and care teams, as it was not fully representative of lived experience. Participants suggested that a “semiology of distress” (id2) be developed, focusing on “emotions, feelings” (id1) or “discomfort” (id4, 5). Adjusting the tool allowed us to reorganize the items and remove 19 of them.

Feasibility, usability coherence and consistency

Although the tool was not designed for psychometric validation or for generating standardized scores, a principal component analysis (PCA) was conducted to explore the internal consistency and visual coherence of key conceptual dimensions (Fig. 4). This analysis aimed to visualize the internal coherence and conceptual alignment of selected psychological dimensions, based on expert-rated items from completed tools. The variables considered in the PCA were mean score for:

- -psychological distress (hetero-evaluated),
- -defence mechanisms (mature, intermediate, immature),
- -motivational profiles (psychosocial, somatic, regulatory).

Those dimensions were selected for their central role in structuring the observation tool and because they aggregate key clinical judgments.

This exploratory analysis aimed to assess the tool’s feasibility, usability and conceptual consistency, rather than to establish construct validity. Given the sample size relative to the number of items, the PCA

results are illustrative and should be interpreted with caution, without inferring a definitive factorial structure. They are used only for exploratory purposes to observe the internal structure of the tool, the empirical organization of the items, and thus to optimize the use of the tool.

Although the PCA shows a certain dispersion between variables (Fig. 4) –for instance, distress hetero-evaluation scores appearing distant from mature defence scores- this spatial separation is consistent with the theoretical expectations of the tool. These dimensions were note expected to covary, but rather to reflect distinct psychological dynamics encountered in EOL contexts.

The factor map illustrates the relative positioning of these variables and highlights several conceptual patterns. For instance, hetero-evaluated distress appeared closer to immature defence mechanisms, suggesting an association between higher levels of distress and the use of less adaptive defence strategies. In contrast, mature defence mechanisms were positioned nearer to motivational indicators, reflecting a different psychological dynamic.

The absence of a tight cluster is not a weakness here: it highlights the complementarity and independence of key clinical indicators, aligned with the observation-based nature of the tool.

Motivation and defence style scores

Overall, the descriptive statistics indicate that the tool was used effectively in clinical settings. The distribution of scores reflects heterogeneity, with satisfactory variability around the mean (represented by a diamond) for each item. The scores appear to be specific, indicating that the respondents provided a variety of answers and were not constrained by the observation tool. The motivation scores were generally high, averaging above 5/10 (Fig. 5). For defence mechanisms, the scores related to mature mechanisms averaged 7.5, whereas those for immature mechanisms averaged 3, reflecting consistency in the scoring of these items (Fig. 6).

Discussion

Few studies have examined how distress is expressed through the EOL decision making. The aim of this study was to support the creation of a tool for observing the psychological determinants involved in complex EOL decision-making. More specifically, the objective was to enable the observation of decision-making dynamics based on psychological indicators and to describe the role of distress in this process. As no such tool was found in the literature, this study developed one that has all the qualities required to meet the research objectives and can be easily integrated into the daily practice of psychologists. After initial work on the literature to form the basis of the tool, a Delphi-inspired method was used. The review phase involved the expertise of clinical psychologists from various French centres. The design and inclusion criteria were refined to make the tool relevant and avoid any potential measurement bias.

Main Findings

The observation tool assesses the emotional (10, 28) and cognitive components of SDM, including patient distress (14, 28, 29), as measured via the Distress Thermometer scale (28), which is relevant in this context (30). Other aspects, such as sadness, guilt, anxiety and dilemmas experienced by relatives and caregivers, are also considered (29, 31–33). Motivations are captured across three domains, namely, the psychosocial, somatic and regulatory domains (34), with attention being given to the logics of reflection (35). Defence mechanisms that aid adaptation and the regulation of negative affect (36) are observed via Chabrol's classification (27, 37). Qualitative and quantitative analyses demonstrate the tool's measurement qualities (38). The dispersion of scores of the selected indicators emphasizes their coherence and relevance. The results support the feasibility and usability of the observation tool. The final version of the tool was reduced to a maximum of 57 questions, resulting in a version described by participants as “streamlined and easy to complete”, promoting engagement that is “relevant to the research aims”. The tool's ergonomic design facilitates its use, and participation in the study was deemed “reasonable”. Psychologists acknowledged its relevance beyond research, highlighting its utility in clinical practice. Using the observation tool “challenges existing practices”, reinforces the “meta-observer” role, and emphasizes the “complexity of refocusing the patient at the centre of discussions, in relation to team issues”. The use of this tool also prompts reflection on the psychologist’s potential “impact” on decision-making. The qualitative interviews indicate that the research question and the use of the observation tool are well accepted. The design of this tool allows for its integration into daily practice, and it is well suited to the non-participatory research context.

The observation tool will serve to better understand the emotional and subjective aspects of EOL decisions, which until now have involved an intersubjective dynamic that has rarely been studied. Although the process often focuses on medical aspects, emotional and affective issues must also be taken into consideration. Furthermore, the tool provides a methodological framework for psychologists to reflect on their practices and interactions during the decision-making process. It enables them to structure clinical observation, promote reflective practice, and question their role and functions in intersubjective interaction during the decision-making process.

Strengths and weaknesses

The integrative literature review was limited to articles published between 2016 and October 2023. Although this may have excluded earlier international contributions, the law reflects clinical practices whit parallels in other countries (e.g., advance care planning) maintaining broader relevance. This decision ensured that the observation tool would reflect contemporary clinical realities and ethical standards in French palliative care. While this may limit the inclusion on earlier international literature, it strengthens the tool’s contextual relevance and applicability in its intended national setting.

Another limitation lies in the absence of a quantitative threshold for defining consensus following the Delphi method: this may be a limitation with regard to the CREDES method of reporting (39) recommendations. However, the study is based on a modified and structured Delphi method, with a qualitative focus, incorporating a pragmatic consensus.

The observation tool has the major advantage of being easy to use and easily integrated into daily practice. Serving as a support for the psychologist's clinical work, it promotes a structured, practical and objective collection of the psychological determinants involved in EOL decision-making process. Although it was developed using a structured approach, it primarily resulted in a qualitative assessment of its scientific relevance. The level of evidence gathered should therefore be interpreted with caution.

It should also be noted that the frequency with which the tool was used by psychologists varied considerably, limiting the number of inclusions and introducing a potential recall bias. Another limitation of the observation tool is the challenge of reconciling clinical work with research activity (40). Additionally, some psychologists questioned their legitimacy in assessing processes within an intersubjective space, as such evaluations may fall closer to systemic approaches, which are on the fringe of their individual clinical practices.

CONCLUSIONS

EOL decisions involve ethical tensions, with some marked by uncertainty and the vulnerability of those involved in the shared decision, particularly in cases of distress. This tool, which was developed from an intersubjective perspective, is designed to simultaneously observe the three key participants in a decision-making process: the patient, their loved ones and the care teams. The tool integrates the observation of subjective components, focusing on the psychological determinants of decision-making processes. The tool allows professionals to assess the impact of distress on decision-making in an EOL context. Ultimately, this work contributes to the development of the Psy2DéPall research project, which investigates SDM at the end of life in cases of distress and explores the intersubjective space coconstructed by the participants. The tool may also be of interest to psychologists, offering an opportunity for them to reflect on their role and positioning in SDM.

Abbreviations

End-of-life-decision
EOL
Shared making-decision
SDM
Principal component analysis
PCA

Declarations

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This noninterventional observation study was conducted within the framework of the human sciences and was based on the analysis of professional practices and clinical decision-making processes. The

study did not modify patient care, therapeutic management, or professional practices. Participating psychologists gave their consent to participate and continued their usual practice without alteration.

Patient consent was not required in accordance with the research methodology and national regulations (France). Patients were informed through institutional communication and public notices available on the institution's website and in participating centers. They could oppose the use of their date for research purposes through a dedicated contact procedure. All collected date were anonymized prior to analysis and securely stored.

The study was conducted in accordance with the ethical principles of the Declaration of Helsinki. On October 5, 2023, the Clinical Research Ethics Committee of the Centre Hospitalier de Valenciennes reviewed the project and issued a favourable opinion published under reference CHV-2023-012.

CONSENT FOR PUBLICATION

Not applicable

TRIAL REGISTRATION

Not applicable

AVAILABILITY OF DATA AND MATERIALS

Due to the sensitive nature of the data (observation of end-of-life decision-making situations), the data is not publicly available. It may be accessed upon reasoned request.

COMPETING INTERESTS

The authors declare that they have no conflicts of interest

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AUTHORS' CONTRIBUTION

CF designed the methodology, analyzed and interpreted the data. AM, VG, MP and IR contributed to the writing of the article through methodological input and a major critical review. All authors read and approved the final manuscript.

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References

1. Bomhof-Roordink H, Gärtner FR, Stiggelbout AM, Pieterse AH. Key components of shared decision-making models: a systematic review. BMJ Open 17 déc. 2019;9(12):e031763. 10.1136/bmjopen-2019-031763 . PubMed PMID: 31852700; PubMed Central PMCID: PMC6937101.
2. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med mars. 1997;44(5):681–92. 10.1016/s0277-9536.(96)00221-3 PubMed PMID: 9032835.
3. Geerts PA, van der Weijden T, Savelberg W, Altan M, Chisari G, Launert DR et al. The Next Step Toward Patient-Centeredness in Multidisciplinary Cancer Team Meetings: An Interview Study with Professionals. JMDH juin 2021;Volume 14:1311–24. 10.2147/JMDH.S286044
4. Haute Autorité de Santé. L'essentiel de la démarche palliative [Internet]. 2016. Disponible sur: https://www.has-sante.fr/upload/docs/application/pdf/2016-12/mc_247_lessentiel_demarche_palliative_coi_2016_12_07_v0.pdf
5. Loi n°. 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie | Légifrance.
6. Rabben J, Vivat B, Fossum M, Rohde GE. Shared decision-making in palliative cancer care: a systematic review and metasynthesis. Vol 38 avr. 2024;38(4):406–22. 10.1177/02692163241238384.
7. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared Decision Making: A Model for Clinical Practice. J Gen Intern Med oct. 2012;27(10):1361–7. 10.1007/s11606-012-2077-6.
8. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, et al. A three-talk model for shared decision-making: multistage consultation process. BMJ 6 nov. 2017;359:j4891. 10.1136/bmj.j4891 . PubMed PMID: 29109079.
9. Légaré F, Stacey D, Pouliot S, Gauvin FP, Desroches S, Kryworuchko J, et al. Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model. J Interprof Care janv. 2011;25(1):18–25. 10.3109/13561820.2010.490502.
10. Damasio AR, Everitt BJ, Bishop D. The Somatic Marker Hypothesis and the Possible Functions of the Prefrontal Cortex. Philosophical Transactions: Biol Sci. 1996;351(1346,):1413–20.
11. Van Hoorebeke D. L'émotion et la prise de décision. Rev FranÃ§aise de Gest. 2008;182(2):33–44. 10.3166/rfg.182.33-44.
12. Van Lander A, Gaucher J, Pereira B, Deneuve-Murol C, Valour C, Begert A, et al. L'identité à l'épreuve de la maladie létale, validation d'un formulaire d'analyse qualitative des entretiens psychologiques. Psycho Oncologie. 2012;6(2):108–19. 10.1007/s11839-012-0373-3.
13. Van Lander A. La détresse psychique. In: Psychologie et Soins Palliatifs- 12 fiches pour comprendre. In Press. 2021. (Fiches de Psycho).
14. Van Lander A, Hermet R, Pereira B, Deveuve-Murol C, Valour C, Gaucher J. A booklet for Psychologists in Palliative Care for Evaluating Distress and Identity Crisis. 2011.

15. Yeun YR, The Effects of Advance Care Planning on Decision Conflict and Psychological Distress. A Systematic Review and Meta-Analysis of Randomized Controlled Trials. J Hosp Palliat Care 1 sept. 2021;24(3):144–53. 10.14475/jhpc.2021.24.3.144.
16. Latham JS, Butchard S, Mason SR. Physician emotional experience of communication and decision making with end-of-life patients: qualitative studies systematic review. BMJ Support Palliat Care 12 avr 2022;bmjspcare-2021-003446. 10.1136/bmjspcare-2021-003446 PubMed PMID: 35414630.
17. Othman EH, Khalaf IA, Zeilani R, Majali S, Nabolsi M, Abdalrahim M. Decision Making Near End of Life: A Qualitative Exploration of the Lived Experiences of Jordanian Healthcare Providers. Cancer Nurs 1 avr. 2023;46(2):152–8. 10. 1097/NCC.0000000000001093 PubMed PMID: 35398869.
18. Van Lander A. La place du psychologue dans la décision médicale partagée en soins palliatifs. Soins mars. 2019;64(833):46–8. 10.1016/j.soin.2019.01.010.
19. Bonnaud-Antignac A, Ferreol M. Rôle du psychologue face à la violence de la fin de vie en soins palliatifs. L'évolution Psychiatrique juill. 2008;73(3):509–16. 10.1016/j.evopsy.2008.05.007.
20. Alric J. Apport du psychologue lors d'une prise de décision médicale difficile. Éthique & Santé. 1 sept. 2008;5(3):173–8. 10.1016/j.etiqe.2008.04.010.
21. Augé C. Psychologue en soins palliatifs: de la place du Sujet à l'hôpital. InfoKara. 2001;16(3):15–7. 10.3917/inka.013.0015.
22. Bohleber W. Le concept d'intersubjectivité en psychanalyse: une évaluation critique. L'Année psychanalytique Int. 2014;1181–214. 10.3917/lapsy.141.0181.
23. Stern DN. Le désir d'intersubjectivité. Pourquoi ? Comment ? Psychothérapies. 2005;25(4):215–22. 10.3917/psys.054.0215.
24. Van Lander A, Rhondali W, Filbet M, Hermet R, Gaucher J. Quelles résonances entre patient et soignants, entre détresse et défenses ? Dialogue entre une psychologue et un médecin. Médecine Palliative: Soins de Support - Accompagnement - Éthique. déc. 2012;11(6):325–30. 10.1016/j.medpal.2012.07.001
25. Elkaïm M. À propos du concept de résonance: Cahiers critiques de thérapie familiale et de pratiques de réseaux. 24 janv 2011;n° 45(2):171–2. 10.3917/ctf.045.0171
26. Dolbeault S, Bredart A, Mignot V, Hardy P, Gauvain-Piquard A, Mandereau L, et al. Screening for psychological distress in two French cancer centers: Feasibility and performance of the adapted distress thermometer. Pall Supp Care juin. 2008;6(2):107–17. 10.1017/S1478951508000187.
27. Chabrol H, Callahan S. Mécanismes de défense et coping. 3ème édition. Paris: Dunod; 2018. p. 320.
28. Holland JC, Andersen B, Breitbart WS, Buchmann LO, Compas B, Deshields TL, et al. Distress Manage J Natl Compr Cancer Netw 1 févr. 2013;11(2):190–209. 10.6004/jnccn.2013.0027.
29. Van Lander A. L'identité à l'épreuve de la maladie létale [phdthesis] [Internet]. Université Lumière Lyon II; 2012. Disponible sur: https://uca.hal.science/tel-03119333
30. Van Lander A, Tarot A, Savanovitch C, Pereira B, Vennat B, Guastella V. Assessing the validity of the clinician-rated distress thermometer in palliative care. BMC Palliat Care déc. 2019;18(1):81.

10.1186/s12904-019-0466-x.

31. Albinsson L, Strang P. A palliative approach to existential issues and death in end-stage dementia care. J Palliat Care. 2002;18(3):168–74. PubMed PMID: 12418367.
32. Fay Z, OBoyle C. How specialist palliative care nurses identify patients with existential distress and manage their needs. Int J Palliat Nurs 2 mai. 2019;25(5):233–43. 10.12968/ijpn.2019.25. .5.233 PubMed PMID: 31116658.
33. Cassell EJ, Rich BA. Intractable end-of-life suffering and the ethics of palliative sedation. Pain Med mars. 2010;11(3):435–8. 10.1111/j.1526-4637.2009.00786. .x PubMed PMID: 20088855.
34. Loi du 9 juin. 1999, visant à garantir le droit à l'accès aux soins palliatifs. 9 juin 1999.
35. De Neys W. Conflict detection, dual processes, and logical intuitions: Some clarifications. Think Reasoning 3 avr. 2014;20(2):169–87. 10.1080/13546783.2013.854725.
36. Chabrol H. Les mécanismes de défense. Recherche en soins infirmiers. 2005;82(3):31–42. 10.3917/rsi.082.0031.
37. Bowins B. Psychological defense mechanisms: a new perspective. Am J Psychoanal 1 avr. 2004;64:1–26. 10.1023/B:TAJP.0000017989.72521.26.
38. Fortin F. Propriétés métrologiques des instruments de mesure (fidélité - validité): Recherche en soins infirmiers. 30 déc 1994;N° 39(4):58–62. 10.3917/rsi.039.0058
39. Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. Palliat Med 1 sept. 2017;31(8):684–706. 10.1177/0269216317690685.
40. Van Lander A, Bioy A. Psychologue, universitaire et chercheur ? Le J des psychologues 1 janv. 2015;324:48. 10.3917/jdp.324.0048.

Figures

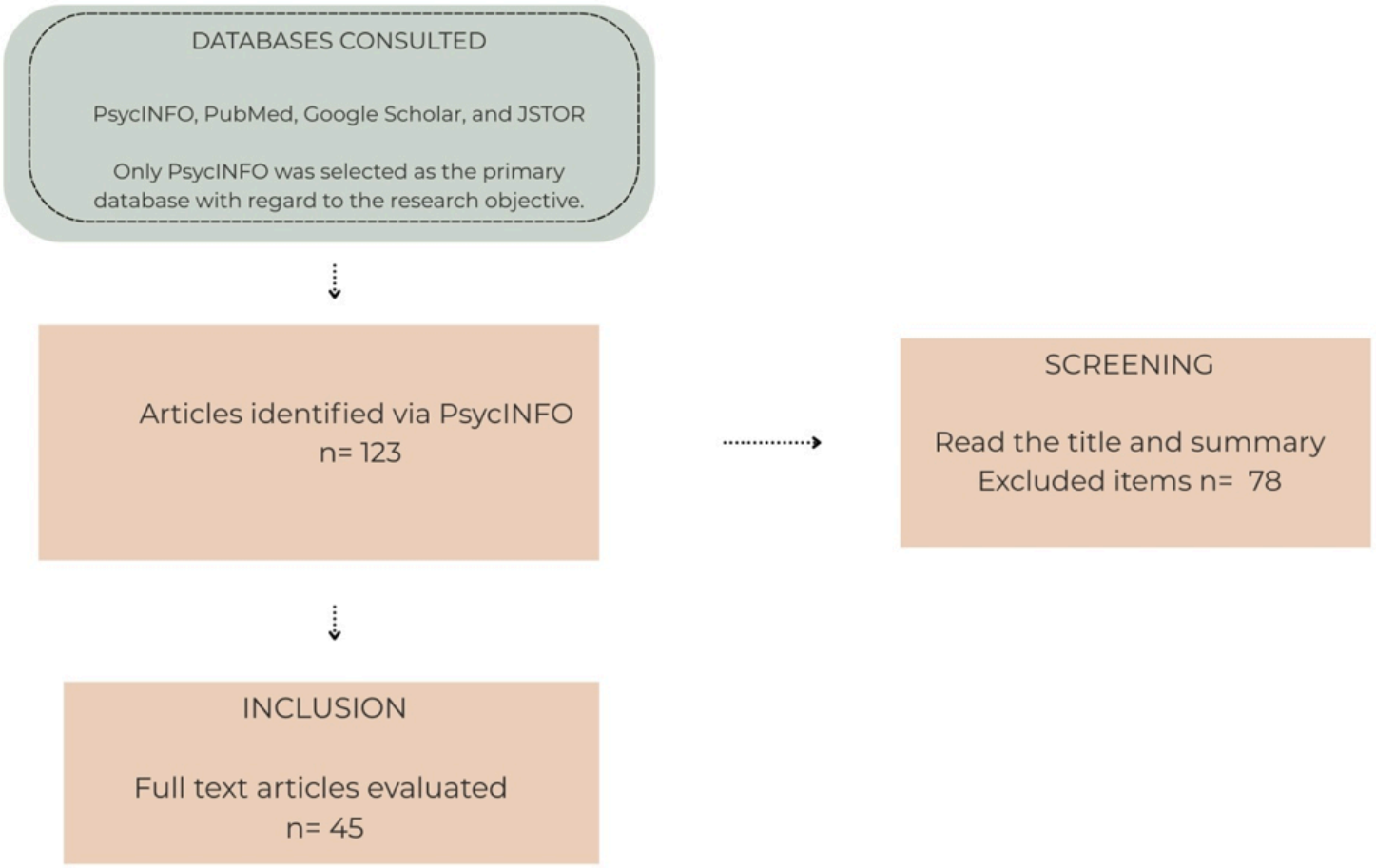


Figure 1

Flowchart of the literature review process

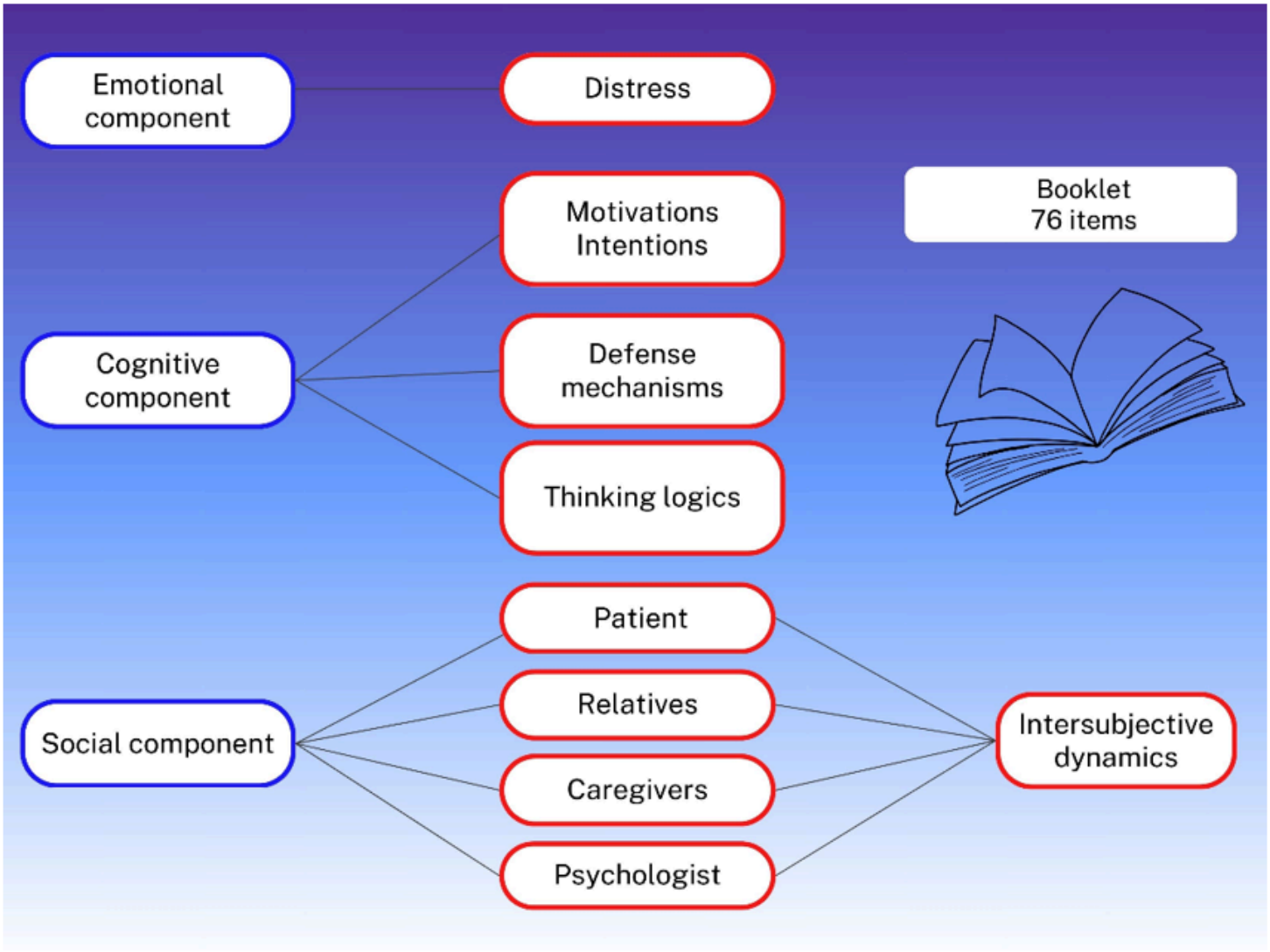


Figure 2

Indicators of the psychological determinants of decision-making

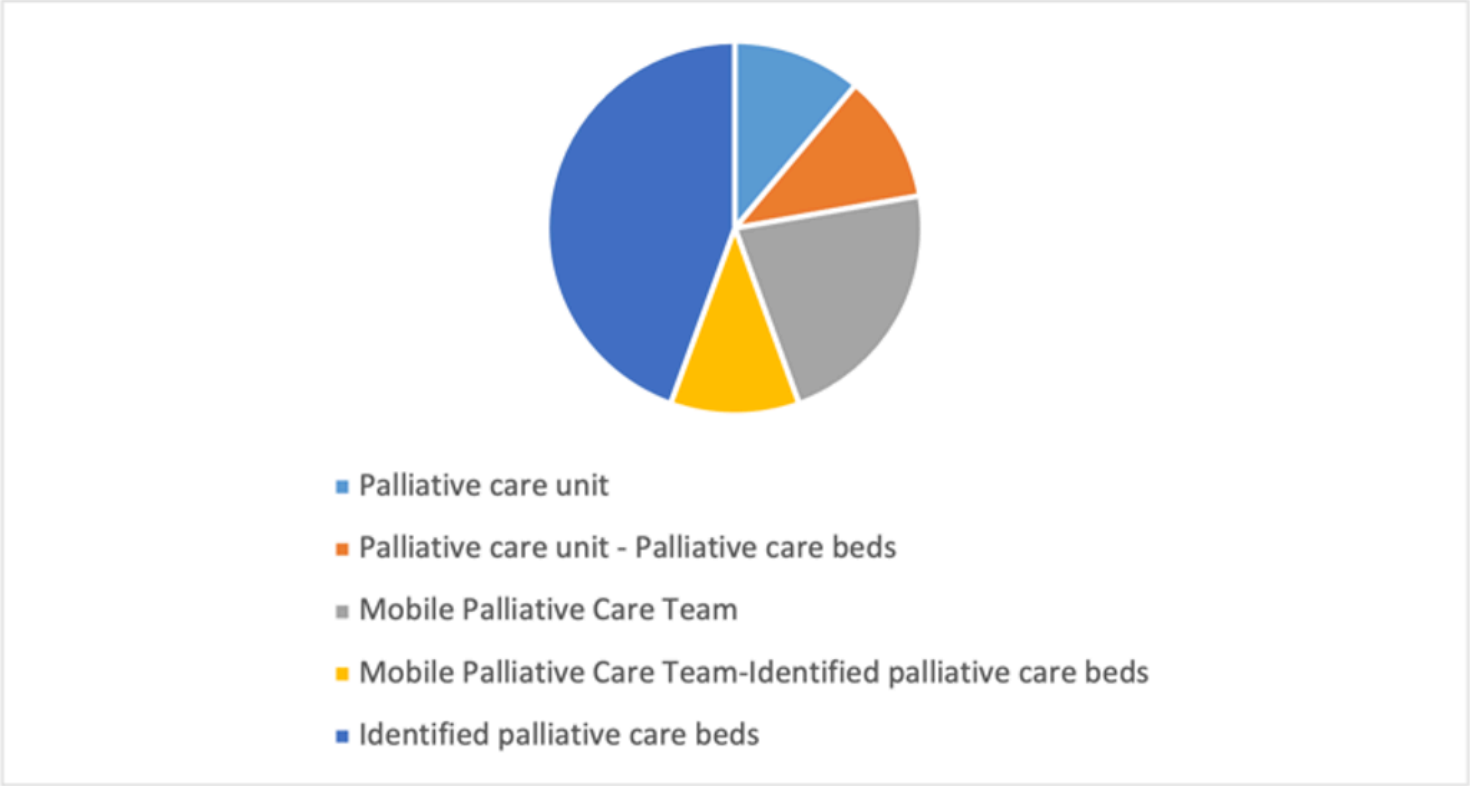


Figure 3

Practice locations of co-investigating psychologists

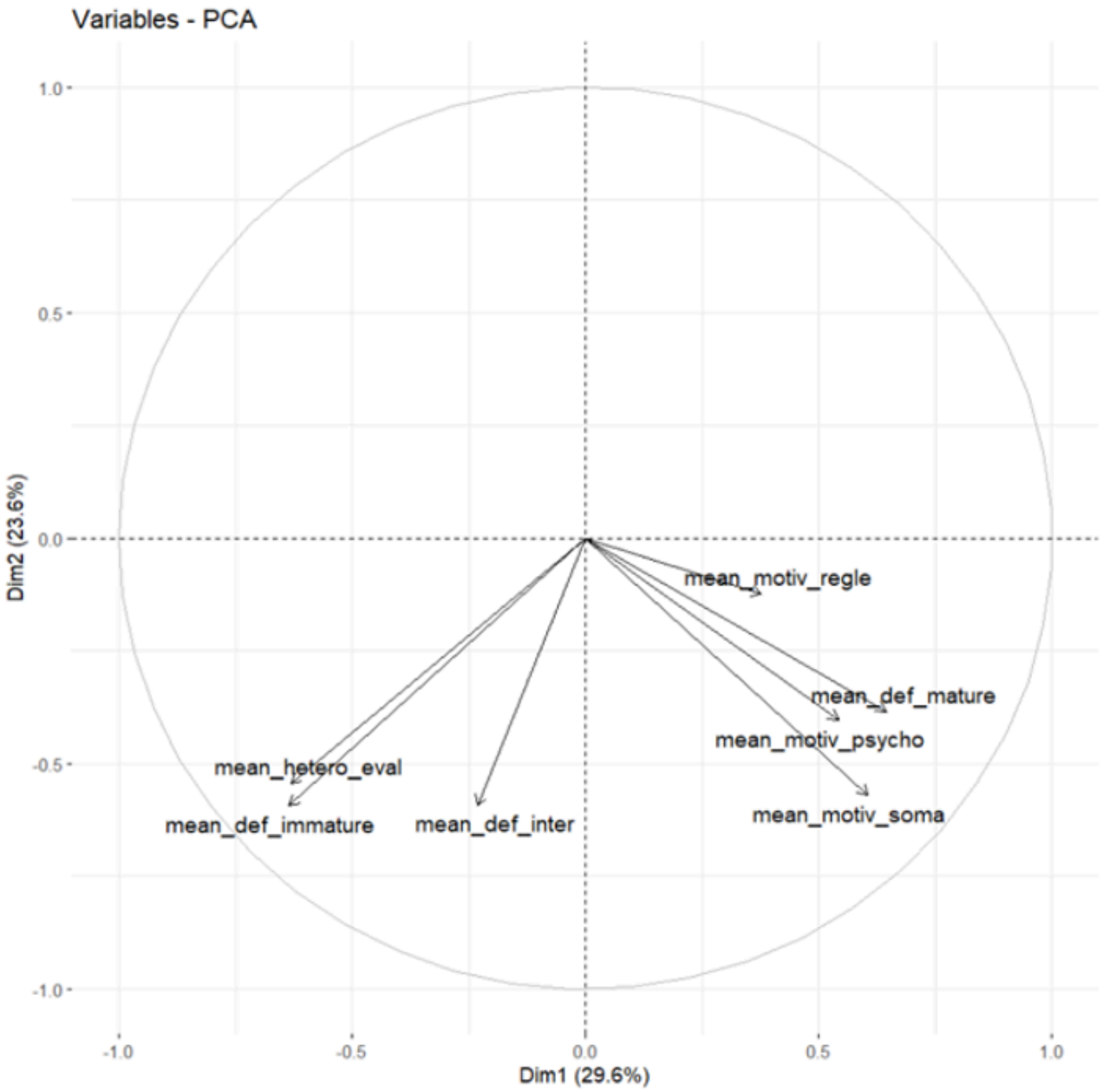


Figure 4

Principal Component Analysis of expert ratings: distress, defence mechanisms and motivation profiles

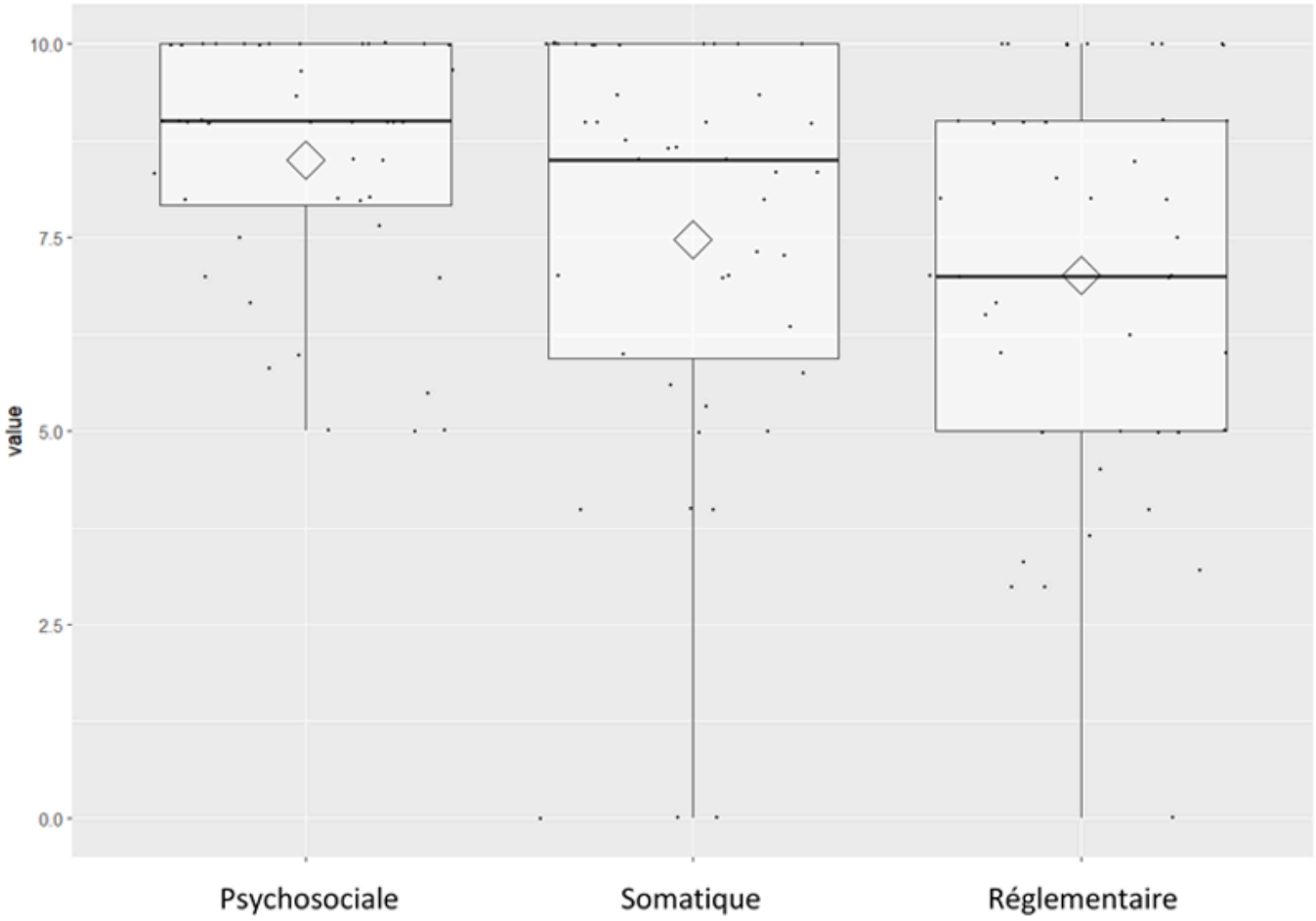


Figure 5

Box plot of motivation scores

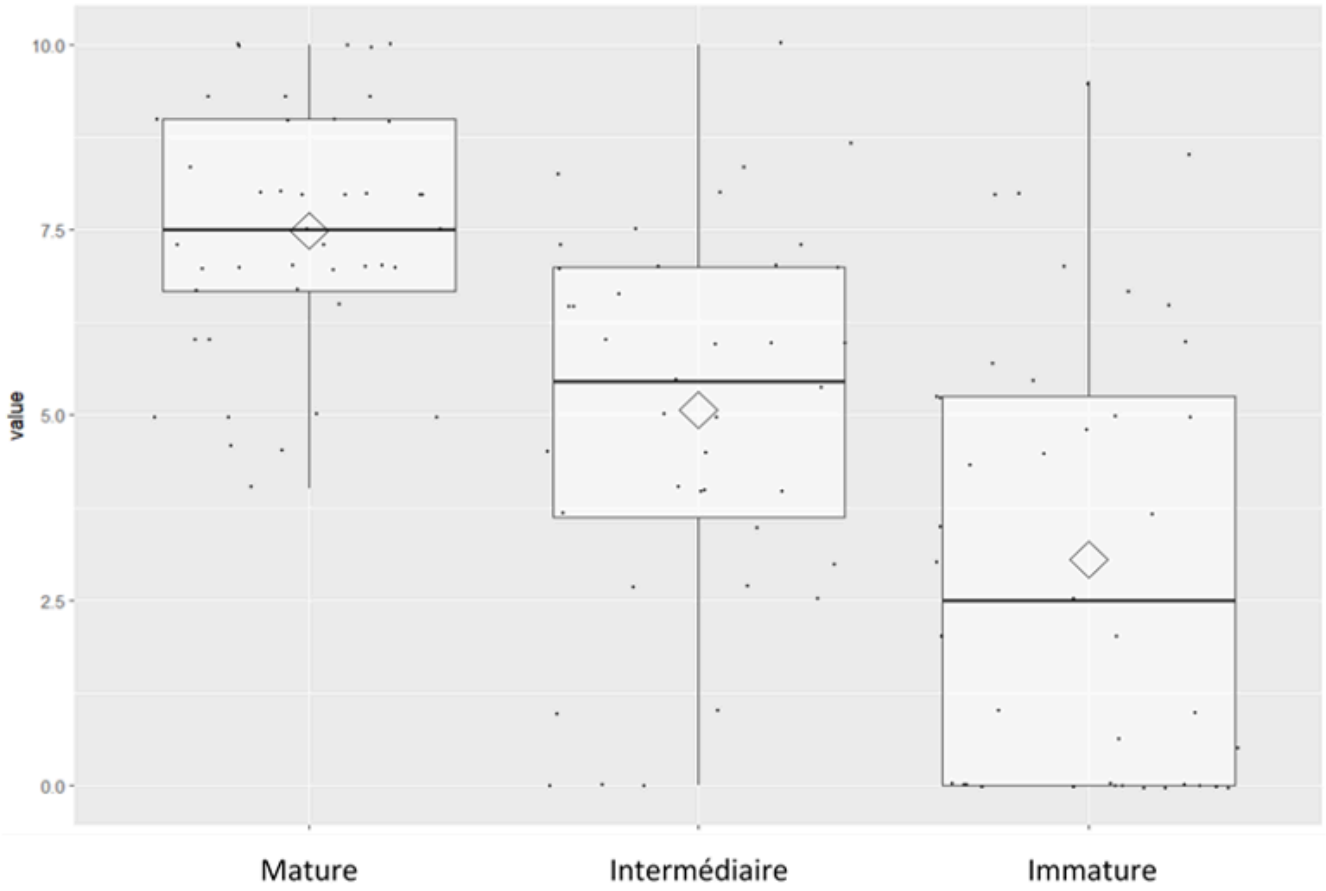


Figure 6

Box plot of defence mechanism scores