

TRUSTED PERSONS OF ELDERLY PATIENTS IN FRANCE: A SCOPING REVIEW

Axe politiques de santé

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While North America and Europe vary in their approach, studies show that patients and professional caregivers are not always taking full advantage of patients' rights. For instance, in France, a trusted person system allows a designated person to support and accompany a patient, with their testimony prevailing over others in end-of-life situations. It seems that the understanding of this legal tool and its implementation by the actors on the ground is not in line with the intent of the law. However, there is no comprehensive inventory of studies on this system in France, particularly for elderly patients. We conduct a scoping review integrating qualitative, quantitative, and mixed studies on the trusted person system in France. The review focuses on frail elderly individuals, their trusted person, their family, and health professionals in the French context.

Research question

- What is the current state of French research on the outcomes of the trusted person system from the perspectives of patients, trusted persons, families, and medical staff?
- We focus on situations where elderly patients are involved.
- Context: the ageing of the population is also associated with an increase in cognitive disorders; deaths in hospital are regularly preceded by decisions to stop or continue life-sustaining treatments; the patient's medical wishes can be transmitted by the trusted person when no advance directive is available; French patients rarely write advance directives.

Method

- Research protocol drafted using the PRISMA extension for scoping reviews (PRISMA-ScR) checklist (Tricco et al., 2018) and registered prospectively with the Open Science Framework on July 23, 2021 (Gontard, Ropaul and Sidre, 2021).
- The review included the following seven steps: (1) identification of the research question, (2) data sources and search strategy, (3) citation management, (4) eligibility criteria and screening, (6) data characterization, (7) data summary and synthesis.
- Bibliographic databases (Pubmed, Embase and CINAHL) and databases with French-written resources (BDSP, CISMEF, LISSA, BNDS, Cairn.info, SUDOC, ScienceDirect) were screened.

Box 1: Search equation for PubMed

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("Proxy"[Mesh] OR "proxy consent"[TW] OR "substitute consent"[TW] OR "medical prox"[TW] OR "patient agent"[TW] OR "health care agent"[TW] OR "health care prox"[TW] OR "healthcare agent"[TW] OR "healthcare prox"[TW] OR "trusted person"[TW] OR "trusted people"[TW] OR "surrogate decision-mak"[TW] OR "substitute decision-mak"[TW] OR "family decision-mak"[TW] OR "patient representative"[TW] OR "proxy decision-mak"[TW] OR "surrogate designation"[TW] OR "substitute designation"[TW] OR "substitute judgment"[TW] OR "substituted judgment"[TW] OR "personne de confiance"[OT] OR "personnes de confiance"[OT] OR "Kouchner law"[TW]) AND ("Aged"[Mesh] OR "aged"[TW] OR "aging"[TW] OR "elder"[TW] OR "Frailty"[Mesh] OR "frail"[TW] OR "Palliative care"[Mesh] OR "palliativ"[TW] OR "Terminal care"[Mesh] OR "terminal care"[TW] OR "end of life"[TW] OR "Critical Care"[Mesh] OR "Intensive Care Units"[Mesh] OR "Resuscitation"[Mesh] OR "Coma"[Mesh] OR "critical care"[TW] OR "intensive care"[TW] OR "resuscitation"[TW] OR "coma"[TW] OR "pseudocoma"[TW] OR "brain death"[TW]) AND ("France"[Mesh] OR "France"[TW] OR "French"[TW] OR french[LA] OR France[Affiliation])
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- Documents (n=1952) published from January 2002 to December 7, 2021, focusing on the trusted person system with French patients above 65 years were identified.
- Documents were included in the final database if: (1) they analyze the outcomes of the trusted person system, as defined by the Kouchner (2002) and Claeys-Leonetti (2016) laws, for the trusted person, the family, the patient or the medical team; (2) they are quantitative, qualitative or mixed-method studies gathering and analyzing data; (3) the publication is an original study and not a review; (4) the study involved patients above 65 years old living in France and (5) the study has been published in a peer-reviewed journal.
- A thematic analysis was conducted. Data were coded using an inductive approach in NVivo 1.5. Nodes were created and semantically grouped into hierarchical themes. Then, themes were named, defined, and organized into overarching meta-themes. Multiple coding of text allowed for exploring relationships between codes using matrix coding analysis.

Descriptive statistics

- The final database contains the 34 articles that met our criteria.
- 64,71% of our included papers collect data on patients, 35,29% on professionals and only 17,65% on trusted persons.
- 29,41% of studies take place in Parisian institutions, 20,59% at national level.

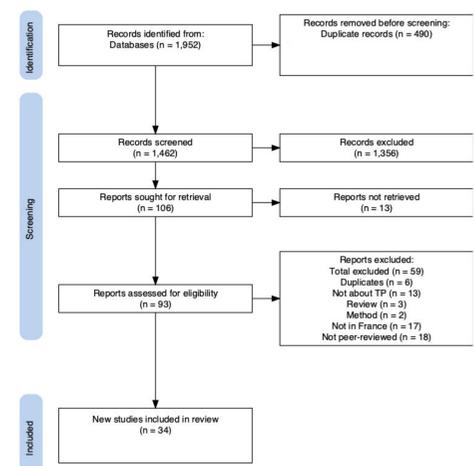


Figure 1: Flow chart describing the selection process

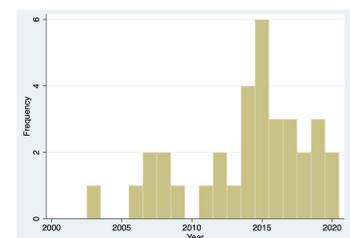


Figure 2: Number of references per year

- 8,82% of the articles collect data in nursing homes
- The vast majority of articles are written by physicians.

Results

- Main measured outcomes in French research: (1) designation of trusted persons, (2) roles actually fulfilled in the field, (3) insertion of the trusted person system in its legal ecosystem, (4) actual criteria of decisions for therapies, (5) information provided to relatives on patients health and (6) quality of death.
- Explanatory factors for the measured outcomes: (1) stakeholders' information, (2) psycho-affective factors, (3) organizational constraints and (4) cultural factors.
- Policy recommendations from the authors and the field: improving stakeholders' information, encouraging discussions on end-of-life issues, modifying designation conditions, changing end-of-life procedures, and strengthening psychological support.
- The literature review highlights imbalances in scientific research on the trusted person, such as the under-representation of social sciences and nursing homes

Limits et perspectives

- Grey literature and articles published in non-peered review journals are excluded
- Future research areas: confusion of the roles of trusted person and family carer, exploring the field of nursing homes and emergency services.
- Public policy recommendation: encourage the emergence of a culture of comprehensive support for patients and their families.