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Maïva Faye-Ropaul, Colin Sidre, Emy Alves, Luigi Gontard. Trusted persons of elderly patients in France: a scoping review. 2023. hal-04164401

HAL Id: hal-04164401

<https://sciencespo.hal.science/hal-04164401v1>

Preprint submitted on 18 Jul 2023

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LIEPP Working Paper
July 2023, n°147

Trusted persons of elderly patients in France: a scoping review

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www.sciencespo.fr/liepp

How to cite this publication:

FAYE-ROPAUL, Maïva, SIDRE, Colin, ALVES, Emy, GONTARD, Luigi, **Trusted persons of elderly patients in France: a scoping review**, *Sciences Po LIEPP Working Paper* n°147, 2023-07-14.

Trusted persons of elderly patients in France: a scoping review

Abstract

Background: 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, the 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.

Objective: To undertake 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.

Methods: Bibliographic databases (Pubmed, Embase and CINAHL) and databases with French-written resources (BDSP, CISMEF, LISSA, BNDS, Cairn.info, SUDOC, ScienceDirect) were screened. Papers published from January 2002 to December 7, 2021, focusing on the trusted person system with French patients above 65 years were identified.

Results: Of 1952 titles and abstracts, 34 documents met our criteria. The main measured outcomes in French research are: designation of trusted persons, roles actually fulfilled in the field, insertion in their legal ecosystem, actual criteria of decisions for therapies, information provided to relatives on patients health, quality of death. The documents also identify explanatory factors, policy recommendations and research avenues.

Conclusion: The trusted person system struggles to develop in a country where the patient-physician relationship is traditionally paternalistic. The results of this research can inform policymakers and researchers in countries with similar cultures and public health characteristics to France.¹

Mots clés: Trusted person, surrogate decision-maker, elderly patient, scoping review, France

¹ The authors particularly thank Pierre Bidault, Antoine Faye and Olivier Musy for their support during the writing of this article. Any error or omission remains the responsibility of the authors. The authors report no conflict of interest.

Introduction

Most deaths occur in hospitals on both sides of the Atlantic (Ferrand et al., 2008). These deaths are often preceded by decisions to suspend or discontinue life-sustaining treatments. For instance, in Europe, three quarters of deaths are preceded by some kind of limitation, with variation between North and South (Sprung et al., 2003).

Besides, patients regularly lack the ability to make decisions in end-of-life situations. Therefore, these discussions often take place between doctors, nurses, and family members or relatives who represent and act as surrogates for the patient's values and preferences (Lesieur et al., 2015; Curtis and Vincent, 2010). Canadian, French, British and European guidelines recommend that families be involved in the decision to withhold or withdraw life-sustaining treatments through a collegial procedure with two physicians, but ethical and legal guidelines can vary widely from country to country (Douplat et al., 2019; Downar et al., 2016, Feral-Pierssens et al., 2018; Royal College of Emergency Medicine 2015; EUSEM 2017).

In France, the system of trusted person allows patients to officially appoint a spokesperson, through a written procedure, as stated in Kouchner (2002) and Claeys-Leonetti (2016) laws transcribed in the Public Health Code (“Code de la santé publique”, hereafter “CSP”, CSP art. L.1111-6 al. 2). Patients have the possibility to choose a close relative, family member, friend or even their general practitioner. The primary mission of the trusted person is to convey the patient's wishes, values and preferences to the medical team in situations where the patient is unable to interact. The testimony of the trusted person then prevails over any other testimony, with the exception of that provided by the advance directives. This system is particularly interesting to activate before the onset of cognitive problems, which can occur frequently in elderly patients. It allows the voice of the elderly patient to be heard at this particular stage of care. This role of witnessing the patient's wishes is particularly reinforced when the patient is in the advanced or terminal phase of a serious and incurable disease. The law (CSP art. L.1111-12) provides that physicians are obliged to enquire about the expression of the patient's wishes. If the patient's wishes cannot be ascertained by means of advance directives, the doctor must obtain the testimony of the trusted person or, failing that, any other testimony from the family or close friends.

Studies in the United States have shown that patients and trusted persons does not systematically share the same opinion about fictive medical situations; that trusted persons are not certain to report the patient's wishes; and even after exchanging information, patients and trusted persons make different decisions in fictive medical situations (Ditto, Danks and Smucker 2001; Shalowitz 2006; Suhl et al., 1994). These studies call into question the effectiveness of the trusted person mechanism as a tool for transmitting the patient's wishes. But beyond the role of transmitting the patient's wishes, the trusted person may fulfil other missions that are valued by the actors. The French legislative framework provides, for example, that the trusted person has a role of accompanying patients during their medical appointments and of advising the patient on medical decisions. However, one may wonder what the reality is in the field.

The other key tool for conveying medical wishes is advance directives. A survey shows that 11% of French people have written their advance directives (Lestrohan, 2018). Meanwhile, in

a survey of US citizens aged 60 years or older who have died of any cause between 2000 and 2010, the proportion of decedents with advance directives increased from 47 % in 2000 to 72 % in 2010 (Silveira, Wiitala and Piette, 2014). In the United States, where the patient-physician relationship is based mainly on the principle of patient autonomy, these advance directives procedures are widely accepted. However, in Europe the patient-physician relationship has historically been paternalistic (Paillaud et al., 2007; Vincent, 1990).

In the French context, the patient-physician relationship is traditionally paternalistic and advance directives are difficult to disseminate among patients as a tool for communicating their wishes. We can then ask what are the effects observed in the field of the right to appoint a trusted person. In particular, we may wonder about the real propensity of patients to exercise this right to appoint a trusted person. Furthermore, we can examine how this system is really understood and applied in the field by the actors in a country with a paternalistic tradition. Answering these questions is essential in order to better inform the legislator on the improvements to be made to the system as part of the implementation of a health democracy. Collecting data from the French field can also inform legislators in countries with similar health, social and cultural characteristics to France - in particular for countries characterized by an aging population with an associated increase in cognitive disorders and a paternalistic tradition in the patient-physician relationship.

To the best of our knowledge, there is no comprehensive inventory of studies carried out on the trusted person system in France, especially for elderly patients. Therefore, we carry out a scoping review integrating qualitative, quantitative and mixed studies to take advantage of their complementarity (Creswell et al., 2011). Scoping reviews aim to map the literature on a particular topic, identify key concepts, gaps in the literature and sources of evidence to inform practice, policymaking, and research (Daudt et al., 2013).

We analyze what is the extent of research in France on patient-centered, family-centered, and medical staff-centered outcomes associated with the trusted person system. In particular, we focus on situations where elderly patients are involved. Elderly people are entering nursing homes at an increasingly advanced age (Mallon, 2012). Furthermore, 150,000 people living in nursing homes died in 2015, which represents a quarter of the deaths recorded throughout France (Muller and Roy, 2018). These facts raise the question of the consideration of the wishes of elderly patients and the use of the trusted person in end-of-life situations.

When an elderly person in full possession of his or her cognitive abilities can designate the trusted person, several issues arise. The trusted person may be confronted with the problem of the end-of-life, which may create particular psychological and organizational challenges. Moreover, the actions of the trusted person may have an effect on the management of the end-of-life of the elderly to some extent. Thus, understanding the actions of the trusted person, their particular challenges and needs can help improve the way society can support vulnerable older people and their families.

Our research protocol was drafted using the PRISMA extension for scoping reviews (PRISMA-ScR) checklist (Tricco et al., 2018) and was registered prospectively with the Open Science Framework on July 23, 2021 (Gontard, Ropaul and Sidre, 2021). In addition to the PRISMA checklist, we used other resources related to scoping review from the Joanna Briggs Institute (Khalil, et al., 2021; Peters et al., 2021; Pollock et al., 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, (5) screening, (6) data characterization, (7) data summary and synthesis.

The PPC (Population, concept, context) has been used in order to conceptualize the review focus (Godfrey et al., 2020). First, the population covered by the study refers to frail elderly individuals, their trusted person, their family and the health professionals surrounding them. Second, the concept at the center of the study is the trusted person system as defined by Kouchner and Claeys-Leonetti laws. We are interested in field and general population data related to this system. Third, we conduct this research in the French context, characterized by an ageing population, an increase of cognitive disorders among elderly patients, the development of home care and a substantial proportion of deaths in nursing homes and hospitals.

Bibliographic databases (Medline via PubMed, Embase via Elsevier and CINAHL) and databases with French-written resources (BDSP, CISMEF, LISSA, BNDS, Cairn.info, SUDOC, ScienceDirect) were screened. Papers published from January 2002 to December 7, 2021, focusing on the trusted person system with French patients above 65 years were identified. Of 1952 titles and abstracts, 34 documents met our selection criteria.

We relied on the six-step recursive framework proposed by Braun and Clarke (2012) to conduct a structured thematic analysis of the selected studies. The main measured outcomes in the field by French researchers are: designation of trusted persons, roles actually fulfilled in the field, relations of trusted person system with other legal tool related to end-of-life and surrogate decision-making, actual criteria of decisions for therapies, information provided to relatives on patients health, quality of death. The documents also identify explanatory factors for the measured outcomes such as stakeholders' information, psycho-affective factors, organizational constraints and cultural factors. The authors suggest policy recommendations such as improving stakeholders' information, encouraging discussions on end-of-life issues, modifying designation conditions, changing end-of-life procedures, and strengthening psychological support. The selected articles propose research avenues on roles actually fulfilled by trusted persons in the field, trusted persons' designation and patients' involvement in medical decision-making.

The rest of the paper is organized as follows. Section 2 details the methodology of the paper. Section 3 presents descriptive statistics. Section 4 describes the meta-themes and themes drawn from our corpus after the conduct of a thematic analysis. Finally, section 5 ends the paper with a discussion of our results and some concluding remarks.

I. Methodology

I.1. Identification of the research question

The review was guided by the question: “what is the extent of research in France collecting or analysing data from the field or general population on patient, family and medical team centered outcomes associated with the trusted person system, when elderly patients are involved?” The aims are to measure the extent research on surrogate medical decision-making has been conducted in France for elderly patients, the methodologies used and whether they are sufficient in describing the outcomes associated with surrogate medical decision-making.

I.2. Information sources and search strategy

The reviewers and an experienced librarian, Colin Sidre, jointly drafted the list of data sources likely to contain articles on our subject and the search strategy. To identify potentially relevant documents, three bibliographic databases were searched from 2002 to December 7, 2021 (except for Cairn.info, December 14, 2021): Medline via PubMed, Embase via Elsevier and CINAHL.

Additionally, we considered seven databases with french-written resources : Banque de données en santé publique (BDSP), Catalogue et index des sites médicaux de langue française (CISMEF) , Littérature Scientifique en Santé (LISSA) , Bibliothèque numérique de droit de la santé et d'éthique médicale (BNDS), Cairn.info, Catalogue du Système Universitaire de Documentation (SUDOC) and ScienceDirect – ScienceDirect was interrogated specifically in french in order to recover french-written resources. French databases include documents from French researchers or focus on the French context. A detailed description of the databases with French-written resources is provided in Appendix 1.

The research equation is built upon our research question. Therefore, we include terms related to “trusted person”; “aged” people or “frailty”. We also include terms related to medical decisions where the trusted person is likely to be involved such as “terminal care”. We restrict the search to documents published between the period of 2002–2021, as 2002 refers to the first entry of the notion of “trusted person” in the French law. We restrict the search to documents related to the French context. In order to retrieve all articles referring to the French context on English-language databases, we also looked for any articles referring to (or being indexed with) France or French people, being originally written in French or being written by authors affiliated with French institutions.

The search strategies were refined through team discussion. When possible, we applied the research equation used for Pubmed, Embase and CINAHL to the French databases. See Appendix 2 for a complete description of our research strategies for each database. Below, we illustrate our research strategy using PubMed as an example.

Medline is indexed with the Medical Subject Headings thesaurus (MeSh). MeSh is a controlled and hierarchically organized vocabulary produced by the National Library of Medicine. It is used for indexing, cataloging, and searching of biomedical and health-related information. However, many resources are not indexed on PubMed, especially recent articles

– the search was performed before the transition to automated indexing. In addition, PubMed will search other databases containing articles not intended to be indexed, for example PubMed Central. Therefore, a comprehensive search using PubMed requires to combine a search in MeSH and a search in free language.

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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 "palliati"[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"[OT] OR "pseudocoma"[TW] OR "brain death"[TW])
AND ("France"[Mesh] OR "France"[TW] OR "French"[TW] OR french[LA] OR France[Affiliation])

```

Box 1: Search equation for PubMed

The process described in Box 1 applies to most databases. As for other information resources, we adapt this method using the same keywords mentioned above, as detailed in Appendix 1.

I.3. Citation management

The search results are exported in Zotero. We named the files using the name of the original database and the number of results. We removed the duplicates using the dedicated function. Then, we have exported each Zotero file in RIS format. Finally, the RIS files are imported on Rayyan.ai for subsequent title and abstract relevance screening. We have proceeded to data characterization of full articles with the help of a form. When full articles were not available, we included the paper in our study if an extended abstract describing methods and detailed results were available to the reviewer team. This stage of the procedure allowed us to detect other duplicates. The form was tested on a subset of the articles and improved through team discussion before being applied to the entire data set.

I.4. Eligibility criteria and screening

Several eligibility criteria have been chosen. To be included in the review, papers needed to focus on the challenges or consequences of the trusted person system for the trusted person, the family, the patient or the medical team. Documents were included in the final database if: (1) they analyze the challenges or the consequences 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 and mixed-method studies gathering and/or analyzing data from the field or from the general population; (3) the publication is an original study and not a review; (4) the study involved patients living in France; the study involved patients above 65 years old; (5) the study has been published in a peer-reviewed journal.

Papers were excluded if they did not fit into the conceptual framework of the study. Two reviewers conduct the screening independently. The first screening focuses on titles and abstracts. The second looks at the integral text. We resolved disagreements on study selection by consensus and discussion between the reviewers.

I.5. Data charting process

After the screening process and the solving of potential conflicts among reviewers, two of them extracted the data using a form. The reviewers have tested the form on a subsample. This process has been followed by discussion and corrections of the form. The test stage ensures that each member of the reviewer team is able to extract the same data from a corpus. After this preliminary stage, both reviewers performed the data charting sequentially.

The charting table records the key information from the selected publications, which are: author(s), year of publication, publication type (published paper, Dissertation, etc.), keywords used by the authors to reference the document (if available), focus of the study (trusted person, mixed trusted person/advance directives, etc.), methods (quantitative, qualitative or mixed-methods); sample composition (trusted person, trusted person, family, health professionals), sample size, institutional context (nursing home, hospital, town medicine, etc.), aims of the study, details for methods and outcomes measurement, key findings that relate to the scoping review question “what is the extent of research in France on patient-centered, family-centered and medical team-centered outcomes associated with the trusted person system, when elderly patients are involved?”. We complete the analysis of the charting table with a thematic analysis, described in Section 4.

II. Descriptive statistics

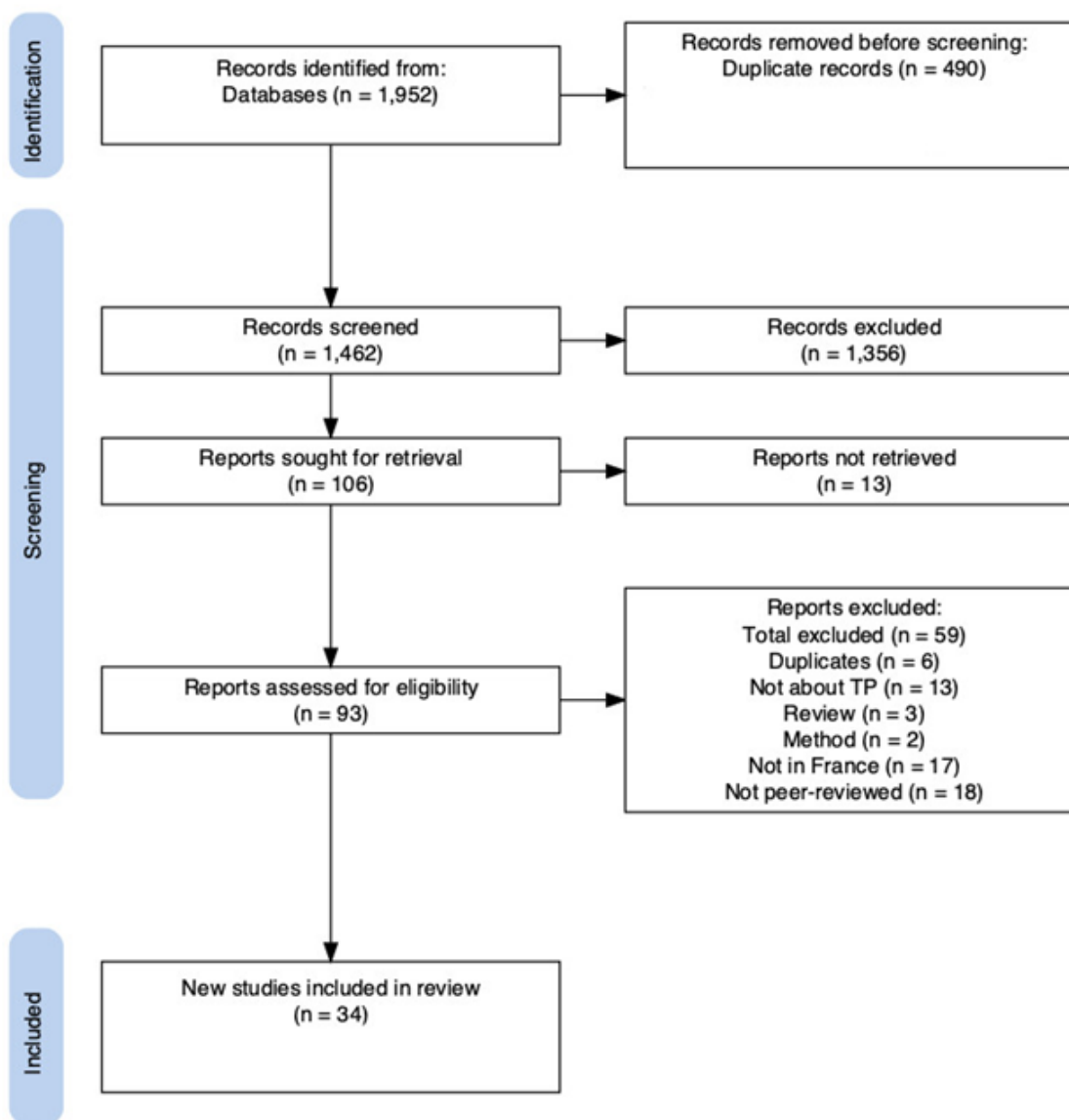
II.1. Selection of the sources of evidence

The initial database search resulted in 1952 references. Table 1 provides the list of data sources before duplicates removal.

Database	Number of references
Pubmed	85
Embase	146
CINAHL	28
BDSP	320
BNDS	123
CISMEF	27
LISSA	951
Cairn.info	70
SUDOC	63
ScienceDirect	139
TOTAL	1952

Table 1: List of data sources before duplicates removal

Graph 1 displays the flow chart describing the selection process. The flow chart was generated using Shiny app, a tool for producing PRISMA compliant flow diagrams (Haddaway et al., 2022). After duplicates removal, we obtained 1462 unique references. After the screening of the titles and abstracts, there were 106 documents. However, at this stage we have detected 6 other duplicates in the database. We have retrieved 93 full texts. We had no access to 13 documents. After the screening of the full texts, we kept 34 references in the final database.



Graph 1: Flow chart describing the selection process

II.2. Characteristics of the sources of evidence

Table 2 in Appendix 2 describes the list of articles included in the final corpus. Analysis of the corpus shows that French research focuses on patients and health professionals, and not on the perceptions, actions or well-being of trusted persons. Indeed, we note that 64,71% (n=22/34) of our included papers collect data on patients, 35,29% (n=12/34) on professionals and only 17,65% (n=6/34) on trusted persons.

We looked at the research area of the first author of each of the papers in our corpus. Almost all papers are written by authors in medicine, gerontology or nursing research (n=33/34). We have one paper written by a team of psychologists (Molli, Cadec and Myslinski, 2007). One paper explicitly mentions the presence of a sociologist, but he is not the first author of the article (Quenot et al., 2021).

Regarding the methodologies used, we have 64,71% quantitative studies (n=22/34), 8,82% qualitative studies (n=3/34) and 26,47% studies with mixed methodologies (n=9/34), among which two papers describe an intervention or a field experiment.

Almost a third of the articles collect data in Paris and its region (29,41%, n=10/34). National level data collection represents 20,59% of our corpus (n=7/34).

Regarding the type of facility where data are collected, hospitals represent the vast majority of our corpus. Indeed, nursing homes represent 11,76% of the corpus (n=4/34) and only one paper collects data from general practitioners (Pavageau et al., 2019). Intensive care units represent 17,65% of the articles (n=6/34), geriatric services in hospitals represent 14,71% (n=5/34) and palliative services and networks represent 11,76% (n=6/34).

We can therefore conclude that there are imbalances in our corpus composed of 34 articles published in peer-reviewed journals. There is room for improvement in the gathering of data on the challenges specifically faced by trusted persons themselves in France in comparison with health professionals and patients. In our corpus, there is an under-representation of the social sciences, qualitative and mixed methodologies, regions other than Paris, nursing homes and town medicine.

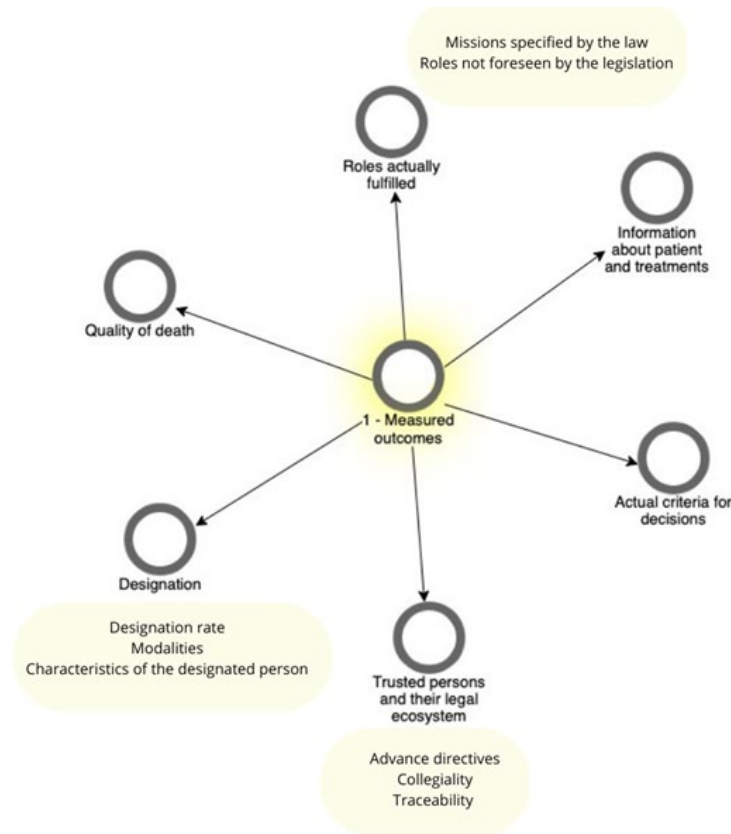
III. Results of individual sources of evidence

The study utilized the six-step recursive framework proposed by Braun and Clarke (2012) to conduct a structured thematic analysis of the selected studies. This approach involves becoming familiar with the data, generating initial codes, identifying themes, reviewing and refining them, defining and naming them, and finally producing the report.

The qualitative data from policy documents was initially 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.

III.1. Meta-theme 1: main outcomes measured related to trusted person

Graph 2 displays the conceptual map summarizing the meta-themes, themes and sub-themes generated by our analysis for meta-theme 1 “main outcomes measured related to trusted person”.



Graph 2: Conceptual map for meta-theme 1 “main outcomes measured related to trusted person”

a) Theme 1: Designation of the trusted person

The articles (n=12/33) report on the practices of designation of trusted persons: its rate, the practical modalities of designation implemented by the actors and the characteristics sought in the designated person.

Sub-theme 1.1 Designation rate

Concerning the designation rate observed in the field, it varies according to the study contexts. Ait Tadrart et al. (2012), Paillaud et al. (2017), Roger et al. (2015) and Martinez-Tapia et al. (2018) report designation rates below 50%. In Ait Tadrart et al. (2012), the vast majority of respondents had never designated a trusted person, either in the hospital (62%) or in the city (82%).

Paillaud et al. (2017, hospitalized patients with cancer, n=426) found that only 15% had designated a trusted person. Roger et al. (2015, intensive care units, n= 625) find that an official surrogate decision-maker designated in a written sheet was reported for 87 (15%) patients, with no significant differences observed between patients admitted from the emergency department or from home, the other hospital wards, and long-term facilities. Martinez-Tapia et al. (2018, comparative cross-sectional study of cancer patients aged 70

years or older versus adults younger than 70 years old in a Parisian hospital cancer, n=236) finds that 40,95% (n=95/232) had designated a trusted person.

Basurko et al. (2013), Trarieux-Signol et al. (2014) and Vinant et al. (2015) report designation rates above 50%. Basurko et al. (2013, Cayenne hospital center wards in French Guyana, n=257) show that half of patients had designated a trusted person during a hospitalization (n=130/252). Trarieux-Signol et al. (2014, haematology department, n=197), finds that 64.5% of patients had designated a trusted person. Vinant et al. (2015, patients with incurable lung or digestive cancer, n=23) find that 73,91% of patients (n=17/23) either had designated a trusted person or previously stated their wishes and desires.

These rates observed in the field are to be distinguished from the rates of patients declaring that they wanted to designate a trusted person, after having received, in the framework of the research, information on the system (e.g. Azoulay et al., 2003; Paillaud et al., 2007). Azoulay et al. (2003) show that the majority of respondents said they would like to designate a surrogate to speak for them should they be incompetent and admitted to an intensive care unit (89,91%, n=7205/8013). Paillaud et al. (2007) indicate that 96.8% of competent elderly patients from the study agreed to designate a surrogate if they were in a life-threatening situation (n= 440/426).

Studies on designation rates are also completed by observations or interrogations on the acceptance rates of the chosen trusted person (e.g. Khetta et al., 2015; Molli, Cadec and Myslinski, 2007; Paillaud et al., 2007).

Subtheme 1.2: Modalities of designation

Regarding the practical modalities of designation implemented by the actors, Paillaud et al. (2017) explain that Spain and France, require a written document by the patient for the designation of a trusted person; whereas some countries, such as Germany and Belgium, require confirmation by a judge.

In hospitals, regarding the administrative formalities, depending on the context, the designation modalities may or may not be standardized. Velter et al. (2016) explain that most participants reported having procedures for designating a trusted person (94%, n = 32). Quenot et al. (2021) indicate that the designation of a surrogate is often proposed at the beginning of the hospital stay, without any specific procedures, implying that there is no standardized process on the delivery of information and discussion on the role of trusted persons before their appointment. Studies in hospitals show that the rate of designation proposal by health professionals is low (Basurko et al., 2013; Degois et al., 2015; Péoc'h and Ceaux, 2009).

In practice, in care units, health professionals do not always know which category of colleague is supposed to propose the designation of the trusted person (Péoc'h and Ceaux, 2009). In the records of cancer patients who died in palliative care units, Perceau et al. (2014) show that there is a low rate of traceability of information conveyed to the patient regarding the trusted person (2.5%). This is a problem because patient information is considered a right and it is the health professional's burden to provide proof of this information in the event of litigation.

The designation is sometimes perceived as a purely administrative act, having to be done primarily in the admissions office (Basurko et al., 2013; Sarradon-Eck et al., 2016).

Sometimes, physicians see the designation as an additional workload (Pavageau et al., 2019). Péoc'h and Ceaux (2009) report that in the course of their practice, caregivers rarely know the name of the trusted person of the person they are caring for, which may indicate a problem with the standardization of information collection and dissemination or a lack of interest in contacting the trusted person.

The studies also describe the actors' perception of how the designation of the trusted person should ideally be done. Patients ask that the appointment be made in front of their general practitioner, in a calm environment, and not in a stressful situation in the hospital (Ait Tadrart et al., 2012). Patients see the interest of the designation in case of a serious evolutionary situation or end-of-life (Pavageau et al. 2019), but also during a serious illness; in case of an accident; before any hospitalization; in case of loss of functional autonomy; for the medical follow-up of a chronic disease; for administrative procedures; in case of memory problems; to fight against isolation and in case of organ donation (Ait Tadrart et al., 2012).

Some studies highlight the difficulty to organize the designation of the trusted person, because of the particularities of hospital admissions. Quenot et al. (2021) show that it is particularly important to anticipate the designation. Indeed, in intensive care units, admissions often take place in an emergency context, with the patient in a clinical state that precludes designation of a surrogate. In palliative care units, Sarradon-Eck et al. (2016) note that when it was the accompanying person who performed the entry formalities, they frequently filled out and signed the form in place of the patient, thus self-appointing themselves as the "trusted person". The authors also observed that in two cases, professional caregivers invested a family member with trusted person status who was not the patient's designated trusted person. These two aforementioned practices are contrary to the French legal provisions on the designation of the trusted person.

Subtheme 1.3: Characteristics of the designated trusted person

Patients primarily identify a family member, with their spouse ranking first, followed by descendants, other family members, friends, and rarely their general practitioners (Azoulay et al., 2003; Basurko et al., 2013; Gignon, Manaouil and Jardé, 2008; Guyon et al., 2014; Martinez-Tapia et al., 2018; Paillaud et al., 2007; Paillaud et al., 2017; Pavageau et al., 2019; Sarradon-Eck et al., 2016; Trarieux Signol et al., 2014). Ait Tadrart et al. (2012) is an exception, in a study based on a geriatric service and an internal medicine service: children are the most cited as a trusted person, followed by the spouse.

According to Paillaud et al. (2007), some patients want to designate two people as trusted persons. These surrogate couples mostly associated a family member and a doctor. This dual designation implies that either elderly patients frequently desire a collegial decision or that they are the vestiges of acceptance of paternalistic care. However, this practice differs from the French legal rules on the designation of the trusted person, where only one individual can be appointed.

Patients look for several qualities when selecting a trusted person: connection, emotional closeness, commitment, responsibility, and trust. A true understanding of the patient is also considered necessary (Pavageau et al., 2019). Sarradon-Eck et al. (2016) also identify practical elements such as geographical proximity, mobility, availability, knowledge of the patient's

medical history, affiliation with the medical sector; They describe psychological characteristics sought by patients when designating their trusted persons, such as psychological strength, stability of the person in an unstable family environment. They also identify affective factors such as dedication, presence, and accompaniment since the disease began.

Rigaud et al. (2016) and Quenot et al. (2021) question what characteristics families and health professionals would look for in designating a person to act as a trusted person in hospitalizations where the patient has not designated one. Pavageau et al. (2019) surveyed general practitioners about their perceptions of the qualities a trusted person should have. The characteristics mentioned by families and health professionals were generally in line with those described by the patients.

b) Theme 2: roles actually fulfilled by the trusted person in the field

Subtheme 2.1: missions specified by the law

According to French laws, a trusted person can perform the following tasks: (1) accompany and assist the patient during medical appointments; (2) be consulted by physicians to give an account of the patient's wishes if the patient is unable to be consulted; and (3) assist the patient in making health-related decisions and participating in the collection of their consent. The articles establish a comparison with the roles assigned by law and the missions carried out in the field.

Assistance during medical appointments and in the patient's decision-making

When trusted persons have been designated, they do perceive assistance during medical interviews as part of their missions (Khetta et al., 2015; Sarradon-Eck et al., 2016; Pavageau et al., 2019). This is also a request from patients (André et al., 2011; Ait Tadrart et al., 2012; Paillaud et al., 2017). Physicians also acknowledge this mission (Pavageau et al., 2019). Trusted persons give patients the strength to keep an active role in medical decision-making processes (Martinez-Tapia et al., 2018). The assistance can be done by retrieving information about the disease, in order to discuss medical information, support the patient in his decision making and to better interact with the doctors (Ait Tadrart et al., 2012; Sarradon-Eck et al., 2016; Nguyen et al., 2017).

Witness of patient's medical wishes

The articles show that patients invest the trusted person with this role of witnessing medical wishes provided for by the law (Azoulay et al., 2003; André et al., 2011; Ait Tadrart et al., 2012; Guyon et al., 2014). This role is also generally known to trusted persons, when they have been appointed (Molli, Cadec and Myslinski 2007; Sarradon-Eck et al., 2016), and by physicians (Gignon, Manaouil and Jardé 2008; Dumont et al., 2012; Quenot et al., 2021). However, Vinant et al. (2015) highlight that the trusted person is frequently designated with an omission of their role as a repository of the patient's wishes. Yet, the spokesperson role is particularly important in the end-of-life phase. For instance, a study of Italian, Spanish, Belgian and Dutch patients showed that 6%, 5%, 16% and 29% designated a surrogate in the last 3 months of life (Evans et al., 2013; Paillaud et al., 2017).

Trusted persons play this role in a limited way. Indeed, they may not be aware of the patient's preferences and wishes. According to Lesieur et al. (2015), in more than three quarters of cases in French intensive care units, the patient's wishes were unknown at the time of decision-making. And yet, when the patient is unable to communicate, the only option for intensive care units staff seeking to discuss the patient's clinical situation in an emergency is to consult the relatives who are present and available. This is critical not only to avoid unreasonable therapeutic obstinacy by pursuing treatments that the patient would not want (e.g. respiratory assistance), but also to understand what the patient would want in order to avoid missed opportunities (Quenot et al., 2021). According to Azoulay et al. (2003), patients and surrogates may not always have the same preferences. As a result, family members and friends are deprived of the information necessary to act effectively as surrogates if values regarding illness and associated issues, such as quality of life and involvement in research, are not addressed among them.

Another issue raised in the literature about this role of witness is the trusted person's ability to faithfully transcribe the patient's wishes. According to physicians, to assist the medical team in making decisions, the trusted person should act on the patient's convictions rather than their own (Pavageau et al., 2019). And yet, instead of relaying the patient's wishes, the trusted person may express their own (Dumont et al., 2012; Guyon et al., 2014; Khetta et al., 2015; Sarradon-Eck et al., 2016). Guyon et al. (2014) found, for example, that while three-quarters of respondents said the patient's opinion took precedence over that of the trusted person, more than half seemed willing to disregard the patient's wishes in favor of the physician's advice to continue or limit care, depriving the device of all its interest (n=376). Similarly, Molli, Cadec and Myslinski (2007) show that when it comes to representing the patient at the end-of-life, some trusted persons refuse to be responsible for the decision to stop treatment and rely completely on the physician. Boyer et al. (2018) note that the decision often remains first and foremost that of the doctors and families, who do not apply the patients' wishes to the letter, but together define their 'best interests'.

The role of the witness is sometimes misunderstood. Patients and trusted persons have sometimes an erroneous perception of the trusted persons' real place in the decision-making process. First, the role of trusted person is better understood in its entirety over time and over the course of the disease (Sarradon-Eck et al., 2016). Second, some people think that they make the decision instead of the medical team (Dumont et al., 2012). Third, the lack of decision-making power of the trusted person, in case of unconsciousness of the patient, seems to be a drawback for many patients (Ait Tadrart et al., 2012).

Trusted persons are aware of their place in the hierarchy of witnesses to the patient's wishes (Gignon, Manaouil and Jardé, 2008; Guyon et al., 2014). Some trusted persons, for example, even mention a protective role with regard to other family members who would like to limit treatment, or to continue treatment, against the advice that the patient would have entrusted to his trusted person (Sarradon-Eck et al., 2016). Some trusted persons have a misconception of their place in the hierarchy, for example, thinking that they will be the sole contact for the physician once they have been designated (Dumont et al., 2012). However, the medical team also relies on the testimony of other family members, in the absence and in the presence of a

designated trusted person (Lesieur et al., 2015; Sarradon-Eck et al.; 2016; Douplat et al., 2019; Quenot et al., 2021).

The preponderance of the trusted person in the hierarchy of witnesses is gladly accepted by the family, given the sense of guilt and emotional charge contained in end-of-life decisions (Molli, Cadec and Myslinski, 2007). This position of the trusted person in the hierarchy of potential testimonies is also welcome for professionals, in particular in the event of a dispute (Sarradon-Eck et al., 2016).

Some articles measure the frequency with which trusted persons were actually consulted by the medical team and may have played a role in decision making. Although physicians generally rely on the family to serve as surrogate decision-makers (Paillaud et al., 2007; Sarradon-Eck et al., 2016; Rwabihama et al., 2020), situations vary (Boyer et al., 2018). For instance, in Douplat et al. (2019), relatives were involved in the decision-making process for 88.1% of patients (n= 96/109, emergency departments). In Khetta et al. (2015), only six trusted persons of the 17 patients who had ever been incapacitated were consulted as part of a medical decision (n=66 patients, hospital services and palliative care network). The study by Péoc'h and Ceaux (2009) notes that caregivers rarely know the name of their patients' trusted person, which raises questions about the place of the trusted person in the medical decision-making process.

Subtheme 2.2: missions actually carried out but not specified by the law

The articles from our final database point out four missions not foreseen by the French legislation on trusted persons. When asked about the role of the trusted person at their side, patients and trusted persons mention assistance with daily living tasks and provision of healthcare (Azoulay et al., 2003; Molli, Cadec and Myslinski 2007; Ait Tadrart et al., 2012; Sarradon-Eck et al., 2016; Pavageau et al., 2019). They confuse the roles of trusted person and informal caregivers. The management of administrative problems, a task often assumed by informal caregivers, is also mentioned as part of the trusted person's duties (Ait Tadrart et al., 2012; Pavageau et al., 2019; Rwabihama et al., 2020). The actors invest the trusted person with the role of mediator in family relations or in relations between the medical team and the relatives (Ait Tadrart et al., 2012; Dumont et al., 2012; Sarradon-Eck et al., 2016). Actors confuse the contact person noted in a patient's records and the trusted person (André et al., 2011; Sarradon-Eck et al., 2016; Pavageau et al., 2019; Rwabihama et al., 2020).

c) Theme 3: Trusted persons and their legal ecosystem

The articles in the database sometimes study the trusted person in conjunction with other devices or concepts arising from the texts governing the end-of-life and shared medical decisions. For example, advance directives are mentioned in 32,35% of the corpus (n=11/34).

Subtheme 3.1: Advanced directives

The results show that patients rarely write their advance directives (Khetta et al. 2015; Lesieur et al. 2015; Roger et al. 2015; Vinant et al., 2015; Douplat et al., 2019; Pavageau et al., 2019; Quenot et al., 2021; Velter et al., 2016). The use of advance directives in France is less widespread than in the United States (Paillaud et al., 2007). The criteria that influence the designation of a trusted person may not also influence the writing of advance directives

(Trarieux Signol et al., 2014). As with the trusted person, the authors also question the presence of a standardized procedure for collecting advance directives (Velter et al., 2016).

If trusted persons are not appointed and advanced directives not written, decisions remain in the hands of physicians (Lesieur et al., 2015). For some patients, it is easier to designate a trusted person while refraining from writing advance directives. This allows the responsibility and emotional burden of decisions to be transferred to another person (Martinez-Tapia et al., 2018). The drafting of advance directives would, however, be necessary to provide a framework for the actions of the trusted person (Molli, Cadec and Myslinski 2007).

Subtheme 3.2: Collegiality

The studies on the trusted person offer a chance to challenge concept of collegiality, which is at the core of French legislation governing the provision of care for people nearing the end of their lives. Even when a decision is made by two doctors in emergency departments, the general practitioner is almost never engaged (Douplat et al., 2019; Lassale-Macke et Violeau 2019). Lesieur et al. (2015) found that in ICUs, less than half of cases engaged a consultant physician in the decision-making process; however, WhWd discussions are frequently held among doctors, nurses, and family members or relatives acting as surrogates. Boyer et al. (2018) found a satisfactory level of compliance with collegiality in a study involving neurosurgeons. Degois et al. (2015), based on 72 records of patients who died in a nursing home, show that the collegiality is mentioned in 31,9% (n=22/72), but collegiality practices complied with legal requirements in less than half cases. Roger et al. (2015) report that decisions can sometimes involve the nursing staff, but that this is not systematic.

Subtheme 3.3: Traceability

Degois et al. (2015), based on 72 records of patients who died in a nursing home, show that the proportions of proposed designation of a trusted person or search for advance directives were insufficient (27.6% and 23.2% respectively). Perceau et al. (2014) highlight the low degree of traceability in the records of patients in palliative care units, particularly regarding the information transmitted to patients about advance directives and the trusted person. In an emergency department, based on a reading of 73 patient records, Lassale-Macke and Violeau (2019) report that the existence of a trusted person and advance directives was noticed in only 1.4% of records. Sarradon-Eck et al. (2016) report that the identity of the trusted person was often missing from the records of outpatients or inpatients on "curative" services who are transferred to palliative care services. This poor traceability of information in end-of-life situations is also documented in other European countries within intensive care units (Roger et al., 2015). Péoc'h and Ceaux (2009) study health providers' knowledge of the concept of traceability alongside trusted person.

d) Theme 4: Actual criteria of decisions for medical treatments

Some articles review the decision criteria actually used by health professionals in end-of-life situations (Boyer et al., 2018; Degois et al., 2015; Douplat et al., 2019; Ferrand et al., 2008; Lesieur et al., 2015; Quenot et al., 2021; Roger et al., 2015; Rwabihama et al., 2020; Sarradon-Eck et al., 2016).

Respect for the opinion of the trusted person and the families in the final decision making process is variable and does not systematically take precedence over that of the medical team (Boyer et al., 2018). In some cases, the patient's wishes, even if expressed in advance directives, are not taken into account (Boyer et al., 2018; Ferrand et al., 2008). For instance, Ferrand et al. (2008) observe in 200 French hospitals that at the time of death, resuscitation was attempted in 542 patients, 98 of whom had NTBR or treatment-limitation orders. Yet, Lesieur et al. (2015) note that the perception of disproportionate and non-beneficial treatment voiced by patient's relatives and the wish to limit treatment voiced by patient may have an effect on decisions to withhold or withdraw life-sustaining treatments.

The presence of a trusted person has an effect on the type of decision made, in particular withholding decisions are more frequent (Douplat et al., 2018). This is in line with the protective role mentioned by some trusted persons, who try to keep their loved ones alive, despite the advice of the medical teams (Sarradon-Eck et al., 2016).

Among the medical criteria used, we can note the notion of foreseeable quality of life based on the prognostic criteria used, the notion of foreseeable disability, age, frailty, patient's overall life trajectory (Boyer et al., 2018; Douplat et al., 2018; Lesieur et al., 2015; Quenot et al., 2021). Lesieur et al., (2015) also add the following rationales : absence of curative strategy, non-responsiveness to medical therapy, advanced or terminal stage of a severe and incurable disease, limited functional autonomy before hospital admission.

Lesieur et al. (2015) show that the type of disease has an effect on decisions. More "active" limitations involve patients with acute organ failures, high severity indexes, and great dependence on life-sustaining therapy. Their study also demonstrate that brain injured patients qualified for a withholding-withdrawing procedure and with the poorest ability to participate directly in decision-making, are more likely to undergo withdrawal rather than withholding of treatment compared to patients with non-neurologic diseases. They also show that patients with chronic respiratory diseases, pre-existing limited autonomy, and/or respiratory failure as reason for admission had their treatment preferentially withheld than withdrawn.

The presence of a mobile palliative care team has an influence on the treatments implemented at the end-of-life, in particular for pain relief (Degeois et al., 2015). Working in a community hospital versus a teaching hospital also has an effect (Rwabihama et al., 2020). This may be related to a different culture of palliative care, collegiality and shared decision-making.

e) Theme 5: Information provided to relatives on the health status of the elderly patient and the therapies applied

The information given to relatives, trusted persons or family, is observed with varying practices. When the patient dies in hospital, in the vast majority of cases professionals have met at least one member of the dying patient's family (Ferrand et al., 2018). Nevertheless, in intensive care units, when discussions are held for end-of-life decisions, relatives are not systematically informed of the decisions and the content of these deliberations. Roger et al. (2015) report a rate of 58% of families informed in a survey of 66 intensive care units in the south of France.

Professionals may also break medical secrecy in order to keep relatives informed of the patient's fate, particularly when no trusted person has been appointed (Quenot et al., 2021; Rigaud et al., 2016). The patient's prior agreement before the information is given is rarely sought (Degois et al., 2015). At the same time, trusted persons are aware that their status makes it easier for them to be informed of the medical situation of their relatives (Sarradon-Eck et al., 2016).

Some studies measure the perception of the quality of communication by trusted persons and relatives. Some articles describe a rather moderate perceived quality (Perceau et al., 2014; Rwabihama et al., 2020; Sarradon-Eck et al., 2016) while others note a high rate of satisfaction (Nguyen et al., 2017). The quality of the information provided to relatives indicates that professionals are paying more attention to those families who will survive the patient's death (Degois et al., 2015). Articles also indicate that the perceived quality of communication influences the level of satisfaction of relatives with care (Nguyen et al., 2017; Roger et al., 2015; Quenot et al., 2021).

f) Theme 6: Quality of death and designation of a trusted person

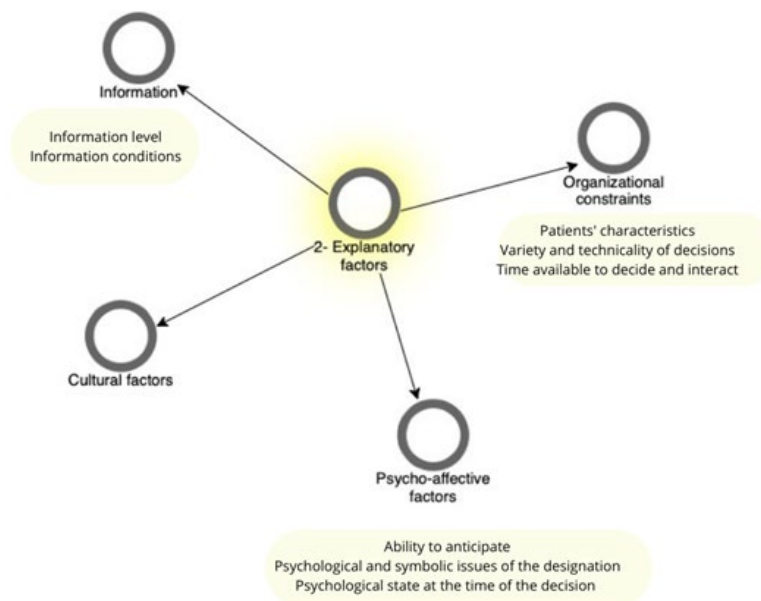
The patient's designation of a trusted person is significantly associated with the nurses' perception of an acceptable death. Other significant factors are the presence of a written protocol for end-of-life care in the department, a higher nurse-to-patient ratio, the nurse's anticipation of death, an NTBR order or treatment-limitation decision recorded in the patient's medical record, adequate pain control prior to death, and information from the family that death was acceptable (Ferrand et al., 2008).

The presence of trusted persons or families at the time of death is not systematic (Ferrand et al., 2008). For example, even during ordinary hospital stays, some trusted persons do not visit their relatives (Paillaud et al., 2007). And, when the patient is dying, families may physically distance themselves, as if to ward off the thought of future suffering (Molli, Cadec and Myslinski, 2007).

Regarding the quality of death in France, in a national study, Ferrand et al. (2008) indicate that only 35.1% of nurses are satisfied with the quality of their patient's death. Roger et al. (2015) state that the quality of death is considered an indicator of the quality of intensive care units.

III.2. Meta-theme 2: explanatory factors

Graph 3 displays the conceptual map summarizing the meta-themes, themes and sub-themes generated by our analysis for meta-theme 2 “explanatory factors”.



Graph 3: Conceptual map for meta-theme 2 “explanatory factors”

a) Theme 7: information

Subtheme 7.1: Information level

Trarieux-Signol et al. (2014) indicate that patients information on the trusted person system can have a positive impact on the rate of designation. However, the corpus shows that the very knowledge of the existence of the trusted person system is variable. Observed rates of knowledge among patients range from 49% (André et al., 2011) to 88.6% (Guyon et al., 2014). Articles by Ait Tadrart et al. (2012), Paillaud et al. (2017), and Martinez-Tapia et al. (2018) note intermediate rates in the patients population. The existence of the concept is rather well known among health care professionals, with rates above 75% (Jouffroy et al., 2014; Jouffroy et al., 2015; Jouffroy et al., 2017). Nonetheless, this knowledge among healthcare professionals may be imperfect. Rwabihama et al. (2020) indicate, for example, that the majority of health care providers cannot name the law that introduced this concept.

Studies indicate varying degrees of awareness of the spokesperson mission of the trusted person. Among patients, André et al. (2011) observes a rate of 35%. Among trusted persons, for Khetta et al. (2015), 56% reported not knowing the roles that this status gives them. Sarradon-Eck et al. (2016) interview 20 trusted persons, noting that most are aware of their spokesperson mission. Nevertheless, the sample is small and the precise figure is not given. Regarding professionals, this mission seems to be known by the majority of them (Dumont et al., 2012; Jouffroy et al., 2014; Jouffroy et al., 2015; Jouffroy et al., 2017). Nevertheless, the particular place that the trusted person should occupy in the decision-making process is not always precisely known. Péoc'h and Ceaux (2009) indicate that professionals are mostly unaware of their professional legal liability and that, except for the advance directives, the opinion of the trusted person takes precedence over any other non-medical testimony.

We have little data on the knowledge of the actors on the missions of accompaniment and advice. For André et al. (2011), the correct definition of a trusted person as "a person you have chosen who is the preferred contact for doctors to receive information about you and who helps you make medical decisions" was chosen by 35% of patients (n=7/20). For Dumont et al. (2012), 52.9% of health professionals explained that the person can help the patient with decisions (n=17/32). Péoc'h and Ceaux (2009) indicate that 89% of professionals (n= 1578/1773) know that the trusted person can accompany the patient in all their procedures. For Khetta et al. (2015), 56% of the trusted persons reported not knowing the roles that this status gives them (n=35/63).

Confusions in the missions to be assumed by trusted persons persist, but in varying proportions according to the studies. The trusted person is confused with the reference person (André et al., 2011; Basurko et al., 2013; Dumont et al., 2012; Guyon et al., 2014; Khetta et al., 2015; Sarradon-Eck et al., 2016; Vinant et al., 2015). There are imprecisions in the role that he or she should actually play in the decision-making process (Dumont et al., 2012).

Regarding modalities of designation, Basurko et al. (2013) report that patients poorly understand how the trusted person is designated. More than half think that an oral choice is appropriate. On the professional side, Dumont et al. (2012) reported that 14.7% knew that designation was not possible for a patient under guardianship and Péoc'h and Ceaux (2009) report that 86% of professionals are aware of the revocability of the trusted person.

Concerning the overall knowledge of patients' rights, the notion of advance directives does not evoke anything in the majority of patients and their families (Guyon et al., 2014; Khetta et al., 2015), while it seems to be rather well known among professionals (Jouffroy et al., 2014; Jouffroy et al., 2017). The notion of collegial procedure is not known to the majority of patients and trusted persons (Khetta et al., 2015). The notions of traceability and professional responsibility in the event of non-compliance with patients' rights regarding end-of-life are known to the majority of professionals (Péoc'h and Ceaux, 2009), while Perceau et al. (2014) assume little knowledge of the concept of 'traceability'. Rwabihama et al. (2020) provide a bleaker picture of professionals' knowledge of patients' rights. Their study of geriatrics professionals revealed a lack of knowledge about advance directives and the surrogate decision-maker for older patients in end-of-life situations. Indeed, only 15% of healthcare professionals (n=22/150) correctly answered at least 75% of the 18 patient-rights questions.

The level of knowledge about the sharing of medical information available to the trusted support person is observed in varying proportions. In André et al. (2011), 66% of patients and 78% wrongly believe that doctors can give medical information directly to their family orally. In Basurko et al. (2013) 77% of professionals (n=124/167) and 85% of patients (n=215/257) are aware that medical confidentiality can be lifted in the presence of the trusted person. In the same study, 73% of professionals and 92% of patients knew that the trusted person could be present during medical interviews.

Subtheme 7.2: Information conditions

Professionals are generally aware of their role in raising patients' awareness of their rights (Rwabihama et al., 2020; Péoc'h and Ceaux, 2009). However, in hospitals, the majority of patients are not systematically made aware by professionals of the content of the tasks of the

trusted person (Khetta et al., 2015; Péoc'h and Ceaux 2009; Velter et al., 2016). In palliative care units, there is little traceability in patients' files of the information provided on their rights (Perceau et al., 2014). General practitioners consider themselves to be essential actors and supporters in this system, but they feel uncomfortable with this topic (Pavageau et al., 2019). In nursing homes, Degois et al. (2015) indicate that although the end-of-life occupies a daily place in the lives of the elderly residents, the problems associated with this period of life seem to be little discussed with the residents, both by professionals and by families.

Some articles describe the identity of the persons or institutions that provide information on the trusted person and the associated rights. One of the practices noted is the delivery of brief information by the admissions office (Sarradon-Eck et al., 2016). It also happens that the designation form is proposed by the admissions office, but without any associated information being provided (Sarradon-Eck et al., 2016; Quenot et al., 2021). When studies find that a health professional in the hospital has taken responsibility for providing information on patients' rights, nurses rank first, followed by doctors (Péoc'h and Ceaux, 2009; Basurko et al., 2013). Other actors participate in the information mission, but to a lesser extent: social worker, midwife, pharmacist, psychologist, medical secretary (Basurko et al., 2013); family, friends, media (Ait Tadrart et al., 2012).

Several articles list reports commissioned by the French government or scientific societies (Degois et al., 2015; Ferrand et al., 2008; Jouffroy et al., 2017; Lesieur 2015; Martinez-Tapia et al., 2018; Paillaud et al., 2007; Péoc'h and Ceaux 2009). They indicate the liveliness of the national debate on end-of-life issues and their accompaniment. However, we did not find any article that precisely measured the extent of media coverage among the general public and how these reports were received by the general population.

The articles also identify the initial training of professionals as an explanatory factor (Péoc'h and Ceaux 2009; Jouffroy et al., 2017; Ferrand et al., 2008). They suggest an improvement in the training of nursing staff and physicians on shared decisions, end-of-life and palliative care issues.

b) Theme 8: The organizational constraints of health professionals

Sub-theme 8.1: Patients' characteristics upon admission

In hospitals, the arrival of patients with major cognitive problems or in an unconscious situation constitutes a first organizational constraint (Azoulay et al., 2013; Douplat et al., 2019; Lesieur et al., 2015; Molli, Cadec and Myslinski 2007; Quenot et al., 2020; Trarieux Signol et al., 2021). Especially since the ageing of the population is accompanied by the development of various chronic and degenerative diseases (Molli, Cadec and Myslinski 2007). The trend towards older and sicker patients increase the number of patients with comorbidities and more unfavourable prognosis (Quenot et al., 2020). These characteristics make it difficult to designate a trusted person at the time of admission, and at the same time amplify the need for a reliable witness to the patient's wishes.

Sub-theme 8.2: Variety and technicality of decisions

Palliative care consultation and the dispensing of painkillers such as opioid analgesics to relieve pain is one of the medical decisions that can be taken at the end-of-life (Degois et al., 2015; Ferrand et al., 2018; Roger et al., 2015). Some deaths are accompanied by a decision of withholding or withdrawing life-sustaining treatments (Douplat et al., 2019; Lesieur et al., 2015; Ferrand et al., 2018). The decisions of withholding or withdrawing life-sustaining treatments can be separated between “do not start”, “do not increase” and “stop” orders (Lesieur et al., 2015). Decisions can be as varied as, for example, to consider limiting vasopressors and dialysis, withdrawing mechanical ventilation such as tracheal extubation (Roger et al., 2015). For patients with advanced cancer, decisions may include whether to continue chemotherapy, use of palliative care teams, parenteral nutrition, transfer to intensive care, and invasive procedures (Vinant et al., 2015).

Sub-theme 8.3: Time available to decide and interact

The time taken to decide on therapeutic limitation is a feature noted by Boyer et al. (2018). However, we did not find any studies linking the time taken to make the decision to the observed treatment choices.

In addition, there has been a reduction in the length of hospitalisation. The interactions of patients and families are thus more limited (Perceau et al., 2014). This observation must nevertheless be tempered according to the pathologies. For example, in the context of cancer, there are repeated interactions between patients, families and health professionals over a long period (Sarradon-Eck et al., 2016).

On the topic of time, it can also be noted that it can be tedious for professionals to go looking for information on the identity of the trusted person, if this information is not directly available to them (Dumont et al., 2012).

Professionals also report that they do not necessarily have the time to provide information on patients' rights (Dumont et al., 2012). This time is also lacking for relatives to prepare for difficult decisions and the near end-of-life (Azoulay et al., 2003).

c) Theme 9: Psycho-affective factors

Sub-theme 9.1: Ability to anticipate

The articles report on the ability and inability of patients and their relatives to project themselves into unfavorable scenarios such as the onset of a disability, old age or death. Young, able-bodied patients may have difficulty imagining the onset of an accident causing a disability (Boyer et al., 2018). The older person may have difficulty in imagining the loss of physical and cognitive abilities associated with ageing as well as death (Molli, Cadec and Myslinski, 2007).

These difficulties in contemplating the worst lead to avoidance behaviour on the part of elderly patients and their relatives. When the subject of the end-of-life is raised in an interview, patients may deflect the subject and shirk their responsibilities. They may then shift the responsibility for end-of-life choices to the family (Molli, Cadec and Myslinski, 2007). As for the family circle, families may be in denial about the possible death of their elderly relative.

It may also happen that the distancing of anxiety-provoking representations leads families to physically distance themselves from the dying relative (Molli, Cadec and Myslinski, 2007).

We can also note a possible instability of the elderly patient's preferences regarding end-of-life decisions. This instability stems from a back-and-forth between the desire to live and the desire to end life, as well as a frequent psycho-affective dependence in the course of aging. It is therefore essential to discern, as far as possible, whether what the elderly person expresses corresponds to their manifest will or whether their desire is the result of a temporary anxiety (Molli, Cadec and Myslinski, 2007).

Some patients are, on the contrary, in the process of accepting their experience of ageing and the near end-of-life. In particular, nursing home residents appear to be less reticent and defensive when death is mentioned and seem to be more accepting of their old age, even if talking about it remains difficult for them (Molli, Cadec and Myslinski, 2007). Spirituality can activate this acceptance behaviour. One study shows that patients who wished to meet a religious person were more likely to write their advance directives (Trarieux-Signol et al., 2014).

For some families, anticipating the end-of-life by appointing a trusted person and writing advance directives is a form of empowerment and increase their satisfaction with care. The exercise of these rights can satisfy their desire to control the end-of-life and to be full partners in care (Molli, Cadec and Myslinski, 2007; Sarradon-Eck et al., 2016; Quenot et al., 2020).

Sub-theme 9.2: psychological and symbolic issues of the designation

Patients highlight their link with the designated relatives through designation. The experience of designating a trusted person is marked by the notion of a relationship, and it also makes it possible to strengthen pre-existing social ties (Pavageau et al., 2019; Sarradon-eck et al., 2016). Some patients would like to have the possibility of designating several trusted persons, which may indicate a difficulty in choosing between relatives (Martinez-Tapia et al., 2018).

Furthermore, pre-existing conflicts in the family may prevent the patient from choosing a trusted person (Azoulay et al., 2003). In these cases, the designation may indeed distort ties. It may also happen that the designation leads to a more favorable outcome by participating in a reconfiguration of the family order and restoring some connections (Sarradon-Eck et al., 2016). Finally, conflicts may emerge when the patient designates a person from outside the family (Ait Tadrart et al., 2012).

There is a risk of overprotection on the part of the trusted person, who, beyond the perceived duty to support the elderly patient, may wish to compensate for the patient's deficiencies, at the risk of infantilizing the patient. It is important to identify this behavior so that the patient is not influenced in their choices when they can still decide for themselves (Molli, Cadec and Myslinski, 2007).

The designation of a trusted person can be experienced by both patients and designated persons as a significant emotional and moral burden, given the responsibilities placed on the shoulders of the trusted person (Ait Tadrart et al., 2012; Molli, Cadec and Myslinski, 2007; Pavageau et al., 2019; Sarradon-Eck et al., 2016). By transferring the burden of responsibility

to the trusted person, the weight of guilt on the part of the family circle can be reduced (Molli, Cadec and Myslinski, 2007).

Finally, the designation of a trusted person sometimes reassures patients (Pavageau et al., 2019). For some, however, the designation is a source of anxiety, with a poor understanding of the content of this device and the fear of not choosing the right person (Sarradon-Eck et al., 2016). Patients may also fear breach of confidentiality by the trusted person (Ait Tadrart et al., 2012).

Sub-theme 9.3: psychological state at the time of the decision

Emotional distance is a quality sought when appointing a trusted person (Pavageau et al., 2019). Indeed, having to represent a loved one or having the feeling of making complicated decisions can cause the trusted person to experience symptoms of distress, anxiety and depression in the short and long term (Azoulay et al., 2003; Basurko et al., 2013; Douplat et al., 2019; Khetta et al., 2015; Molli, Cadec and Myslinski 2007; Sarradon-Eck et al., 2016).

This can lead the trusted person to shirk their responsibilities and relinquish any position by relying completely on the doctor (Molli, Cadec and Myslinski, 2007). Some lose sight of the big picture and get stuck on details when making decisions (Azoulay et al., 2003).

d) Theme 10: Cultural factors

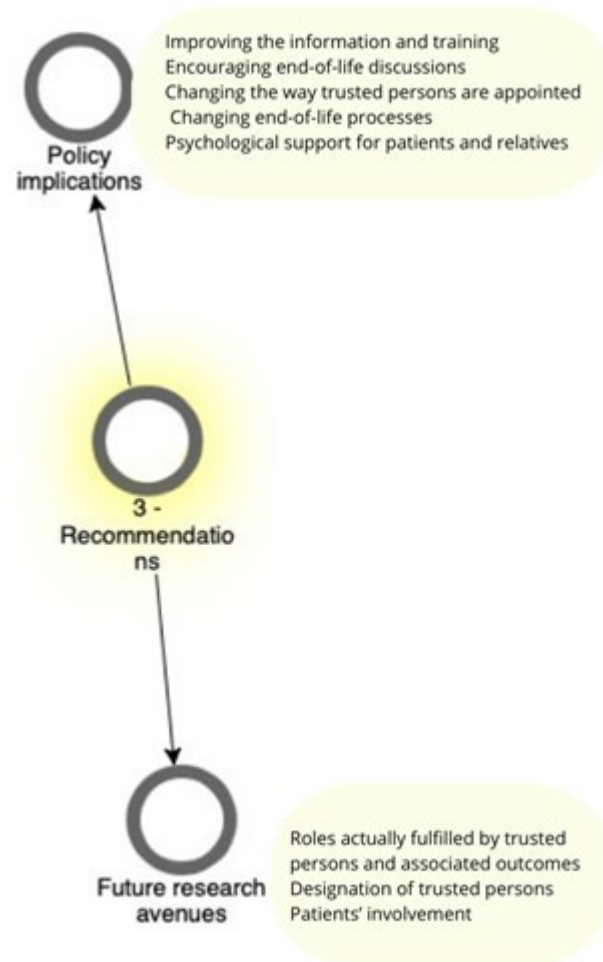
The culture of shared decision-making (Ferrand et al., 2008) and the national culture (Trarieux-Signol et al., 2014) may explain the observed behaviors.

France is a country where patient-doctor relations are traditionally paternalistic. This generates in the actors, patients, relatives and professionals, the feeling that the decision belongs to the doctor, holder of scientific knowledge and medical information, with a hierarchical superiority over patients and families (Azoulay et al., 2003; Khetta et al., 2015; Paillaud et al., 2007; Roger et al., 2015). Nevertheless, the evolution of French society is leading to a demand for shared decision-making (Azoulay et al., 2003; Khetta et al., 2015; Martinez-Tapia et al., 2018). Patients demand to be informed and to participate in medical decisions concerning them, as well as the involvement of their relatives (Azoulay et al., 2003; Lesieur et al., 2015; Martinez-Tapia et al., 2018; Paillaud et al., 2007; Paillaud et al., 2017; Velter et al., 2016; Vinant et al., 2015). The trusted person scheme encourages a change in the relationship between doctor and relatives, giving them a space in the care of the patient (Sarradon-Eck et al., 2016).

The demand for shared information and decisions is not uniform in the population. Factors that may influence the propensity of patients to want to be involved are age, number of people in the household, number of children, number of daily medications, having cancer versus another disease (Martinez-Tapia et al., 2018; Paillaud et al., 2007; Paillaud et al., 2017).

III.3. Meta-theme 3: recommendations

Graph 4 displays the conceptual map summarizing the meta-themes, themes and sub-themes generated by our analysis for meta-theme 3 “recommendations”.



Graph 4: Conceptual map for meta-theme 3 “recommendations”

a) Theme 11: Implications in terms of public policy

The recommendations for public policies or changes in practices in institutions are made either by the authors of the studies, or they come from the professionals, patients and trusted persons interviewed, or they come from the observation of innovations implemented in the field.

Sub-theme 11.1: improving the information and training provided to stakeholders

The studies recommend training for professionals, patients and families. Information for professionals on patients' rights could be improved by implementing multi-year training courses (Basurko et al., 2013; Rwabihama et al., 2020). Informing professionals about the end-of-life, its associated rights and the acquisition of a culture of shared decision-making can also be achieved by modifying the initial training of professionals (Ferrand et al., 2008; André et al., 2011). However, it is not easy to transfer theoretical knowledge to real practical implementation and understanding (Péoc'h and Ceaux, 2009). End-of-life guidelines and practical tools can be put in place (Douplat et al., 2019; Lassale-Macke and Violeau, 2019).

Information to patients and families on end-of-life rights could be provided through a public information campaign (Guyon et al., 2014). During hospitalisation, professionals could provide an information booklet (André et al., 2011, Quenot et al., 2020; Trarieux Signol et al., 2014). Articles stress the importance of providing information to patients and their relatives to encourage trusted person designations and the writing of advance directives (Basurko et al., 2013; Khetta et al., 2015; Martinez-Tapia et al., 2018).

Sub-theme 11.2: encouraging end-of-life discussions

The articles recommend encouraging discussions about the end-of-life. In nursing homes, end-of-life conversations between the resident and their doctor can help to anticipate the end-of-life and improve management (Degois et al., 2015). Anticipation of end-of-life wishes is indicated as essential, especially for chronically ill patients, prior to any admission to emergency or intensive care units (Douplat et al., 2019; Quenot et al., 2020). End-of-life discussions should also be encouraged within families (Azoulay et al., 2003; Molli, Cadec and Myslinski, 2007).

Sub-theme 11.3: changing the way trusted persons are appointed

The articles suggest changes to the arrangements for appointing the trusted person. The time of hospitalization, which is stressful and surrounded by numerous administrative procedures, is not perceived as an appropriate time for the designation (Ait Tadrart et al., 2012; Basurko et al., 2012; Khetta et al., 2015). Several articles indicate that designation should be encouraged at a distance from the hospitalization. This could be done with the general practitioner (Ait Tadrart et al., 2012). However, there are practical and psychological obstacles to this practice for general practitioners (Pavageau et al., 2019).

It would also seem appropriate to separate the moment of designation of the trusted person from the moment when the referent person is appointed. This avoids fuelling confusion between these two roles (Sarradon-Eck et al., 2016).

In hospitals, the proposal to designate the trusted person should be made by doctors as this designation can be considered a medical act (Sarradon-Eck et al., 2016). It would be useful to set up a reference person within hospitals on the issue of patients' rights, a member of the medical or paramedical team, in order to provide patients and their families with all the information they need and to give them a space for reflection (Khetta et al., 2015).

Sub-theme 11.4: Changing end-of-life processes

Studies point to ways to improve end-of-life processes. The voice of the trusted person should be better heard by professionals and communication with them should be improved (Boyer et al., 2018; Rwabihama et al., 2020; Sarradon-Eck et al., 2016). The *carte vitale* should contain information on the trusted person and advance directives to facilitate access for health professionals (Guyon et al., 2014). The involvement of general practitioners in collegial procedures could be strengthened, given their familiarity with patients (Douplat et al., 2019). A qualitative evaluation of the processes surrounding the end-of-life in institutions should be carried out (Ferrand et al., 2008; Péoc'h and Ceaux 2009).

Sub-theme 11.5: Psychological support for patients and relatives

Several articles highlight the need for enhanced psychological support for patients and relatives (Boyer et al., 2018; Khetta et al., 2015; Molli, Cadec and Myslinski 2007; Sarradon-Eck et al., 2016). Accompaniment of trusted persons at the time of decision-making is necessary to promote the search for the patient's values and to manage the short and long term psychological consequences of the testimony given (Boyer et al., 2018).

Psychological support also seems necessary at the time of the designation of the trusted person, both for the patient and for the designated person. The psychologist, trained in listening and accompanying painful situations, could guide the patient, support them in this projection into these difficult scenarios and detect any pressure exerted by the family circle. The psychologist can also explain to the designated person their role and help them anticipate the psychological impact of their future actions (Khetta et al., 2015; Molli, Cadec and Myslinski 2007; Sarradon-Eck et al., 2016).

b) Theme 12: Recommendations for future research

Sub-theme 12.1: roles actually fulfilled by trusted persons and associated outcomes

For example, Martinez-Tapia et al. (2018) suggest that additional study should take into account the true significance of a patient's surrogate in the decision-making process. Future longitudinal studies will enable researchers to address additional research questions about the impact of patients' involvement in decision-making on outcomes, particularly determining whether patients who are highly involved exhibit improved quality of life, adherence to treatment, and satisfaction with care.

Sub-theme 12.2: designation of trusted persons

Regarding trusted persons designation, according to Paillaud et al. (2007), the readiness of family members or general practitioners to act as surrogates should be determined by additional study in geriatric populations. According to Quenot et al. (2020), their study on the factors loved ones consider crucial when choosing a trusted person has led to some intriguing new lines of inquiry. First, it would be of interest to plan a follow-up meeting to rank the significance of the various criteria, perhaps using the concept mapping methodology. Second, a more comprehensive, multicentre research would be beneficial to confirm the herein identified criteria and guarantee that the results are not centre-specific. Potential factors could also be controlled in a multicentre study. According to Trarieux-Signol et al. (2014), they did not investigate the patient's motivations for selecting a trusted person or whether trusted persons truly afford opportunities for conversation or are merely administrative formalities. It might have been interesting to solicit professional views to determine how they view trusted persons and advance directives.

Sub-theme 12.3: patients' involvement

Regarding the patients' willingness to receive information and to have an active role in medical decision-making, Paillaud et al. (2017) propose a study of preferences regarding participation in particular decisions, such as chemotherapy, in addition to an investigation into the real choices made by individual patients. According to Vinant et al. (2015), it is still challenging to provide comprehensive information to patients who are in the advanced stages

of cancer because keeping optimism is known to be a major motivator for them. In order to determine how best to inform patients in a larger population, studies must be conducted in France to determine how much knowledge patients want about their oncology prognoses.

IV. Discussion and concluding remarks

Our scoping review identifies the key concepts underpinning the French research collecting and analyzing data in the field and general population on trusted persons of elderly patients. We find six main measured outcomes. We identify explanatory factors and recommendations drawn from the authors and their data.

In our corpus, the main type of evidence available relies on peer-reviewed articles written by physicians in hospital context and with the collect of data mainly on patients and health professionals. Therefore, we can infer that our corpus of 34 papers from peer-reviewed journals contains imbalances. The collection of information on the particular difficulties encountered by trusted persons themselves in France is under-represented in contrast to medical personnel and patients needs. The social sciences, qualitative and mixed methodologies, locations other than Paris, nursing homes, and town medicine are underrepresented in our corpus.

One may wonder whether the under-representation of social sciences in our corpus is related to the databases initially used. However, the database search was exhaustive, with a diversity of databases used (Medline via PubMed, Embase via Elsevier, CINAHL, BDSP, CISMEF, LISSA, BNDS, Cairn.info, SUDOC, ScienceDirect). Moreover, out of the 34 references in the corpus, 15 come from English-language databases, 11 from French-language databases, and 8 are on both types of databases at the same time. This fully justifies the double search strategy that has been put in place using French-language and English-language databases.

The under-representation of social sciences could also be due to a bias in the reviewers' training (economics, management and sociology). Indeed, we have as selection criteria the presence of a quantitative, qualitative or mixed methodology in the collection and analysis of data. However, a researcher in economics, sociology or management does not necessarily have the same vision of what is a data collection and analysis compared to other researchers from other social sciences. This has led our team, for example, to exclude many papers written by lawyers.

A limitation of our study is that we only included articles published in peer-reviewed journals. We chose this selection criterion in order to ensure that the articles selected had satisfactory quality standards in terms of methodological data collection and analysis. This leads us to exclude, for example, all practice theses and doctoral theses provided by the SUDOC database. The study could be completed by examining the theses that have been completed or are in progress, which has not been done in this first scoping review due to human resources issues.

We can also note that the under-representation of retirement homes and town medicine in our corpus could be explained by the way research in medicine is done in France. We note that the majority of the authors in our corpus are physicians attached to university hospitals. In order to produce their research work, they naturally rely on the field that is most easily accessible to them, namely their own hospital.

Our findings have several implications. First, we identify gaps in French research on trusted persons of elderly patients. There is room for improvement in the gathering of data in some specific services of hospital, such as admission services for instance. Although admission service collect of information on the trusted person may be one of the steps in the day-to-day work, there is only one article specifically on this service in our final sample (Guyon et al., 2014). It also seems to us to be in the public interest to develop research in other services such as palliative care units and long-term care services. In the two aforementioned departments, patients often have complex medical conditions that require urgent and often life-saving interventions. In such cases, trusted persons may play a critical role in determining the best course of action for the patient. Developing research in those services can deepen the reflection procedures to improve patient outcomes, ensure patient autonomy and dignity and reduce conflicts. There is also a need to accelerate the collection of data in nursing homes and town medicine, given that these two institutions are central points of access to care for the elderly.

Further studies could be conducted on comparing the health preferences of patients and trusted persons. For example, preferences for medical treatments could be compared using a proven method in economics, the discrete choice experiment. The role of spokesperson is central to the trusted person scheme. It is important to collect French data to see whether treatment characteristics such as length of life extension, post-therapy quality of life, the burden of hospitalization and the risk of side effects are valued in the same way by the patient and by the trusted person. Especially since instead of relaying the patient's wishes, the trusted person may express their own (Dumont et al., 2012; Guyon et al., 2014; Khetta et al., 2015; Sarradon-Eck et al., 2016).

Our scoping review also shows the lack of papers published from large-scale studies. For example, we did not find recent national statistics representative of the general population on the percentage of patients who have designated a trusted person. There is therefore no global view of this component of health democracy.

One article suggests that the *carte vitale* should contain information on the trusted person and advance directives to facilitate access for health professionals (Guyon et al., 2014). However, a tool for sharing medical information was implemented in France in 2018: the shared medical record. We also found no national statistics on the percentage of patients who have filed their trusted person form and advance directives on their shared medical record. The shared medical record, commonly referred to as the DMP, now integrated with the new "My Health Space" service, is a digital health record for securely storing health documents. The DMP also allows you to share this information with the healthcare professionals of your choice to improve your medical follow-up, including in the event of an emergency. However, only 10% of the general population has activated their DMP, according to *ameli.fr*, the Assurance Maladie website. It would be interesting to carry out research into the motivations for activating a DMP and the propensity to deposit information on medical wishes.

Several articles (Degois et al., 2015; Ferrand et al., 2008; Jouffroy et al., 2017; Lesieur 2015; Martinez-Tapia et al., 2018; Paillaud et al., 2007; Péoc'h and Ceaux, 2009) mention reports commissioned by the French government or scientific societies. They show how lively the national conversation is about problems surrounding the process of dying as well as its

accompaniment. However, we were unable to identify any article that accurately assessed how widely these stories were covered by the media and how the general population reacted to them. In this context, the analysis of textual data could be mobilized to study the media discourse, both in the press and on social networks, on these elements of health democracy that are the trusted person device and the advance directives.

Boyer and coauthors point out the length of time required to choose a therapeutic restriction (2018). However, we were unable to identify any studies connecting the length of time it took to make a choice to the actual therapy options. This could be an avenue for future research.

Additionally, the duration of hospitalization has been shortened. As a result, there are fewer interactions between patients and their families, whereas in some situations, like cancer, there are frequent interactions over an extended period of time between patients, families, and health workers. (Sarradon-Eck et al., 2016). It would be interesting to observe the degree to which repeated interactions lead to cooperation and improved outcomes for all parties involved.

On the subject of time, it should be noted that it can be time-consuming for professionals to go looking for information on the identity of a trusted individual if this information is not readily available to them. (Dumont et al., 2012). It would be interesting to observe the strategies created by medical teams to maximize the retrieved information while assuring quick patient care in services characterized by a lack of time, such as emergency services.

After reading our corpus, two public policy recommendations seem fundamental to us to be implemented in the French context. First of all, beyond a shift to a patient-physician relationship based on shared decision-making, it is essential to develop what could be called a culture of support for patients and their families. Indeed, numerous papers have highlighted the short- and long-term psychological difficulties that patients and their loved ones face during two critical stages: designation and medical decision-making.

Several solutions were mentioned in our corpus, including the involvement of psychologists, the general practitioner raising awareness of patients and relatives, and the creation of a reference person within hospitals to spread information and provide a space for discussion. The intervention of psychologists appears to us to be especially important to promote. Indeed, the corpus demonstrates that general practitioners are not always at ease discussing these problems. Furthermore, general practitioners and hospital staff do not have the time to listen to patients and their families in detail. They also lack the time and possibly the expertise to recognize the family dynamics and psychological mechanisms at action in the designation and therapy preferences voiced by patients and their relatives.

Although the development of psychologist intervention is required, the promotion of a culture of support necessitates a broader base of theoretical and practical knowledge in the initial and continuing training of health professionals. Several articles in our corpus have emphasized the significance of health professionals training in promoting the exercise of patients' rights. An article in the French newspaper *Le Monde*, dated March 2023, states that since 1997, universities have been required to offer palliative care teaching in the second cycle of medical studies, but student participation in these modules has remained optional. In initial training, end-of-life issues occupy between six and ten hours in the second cycle, depending on the

faculty. The role of general practitioners in the private sector is very important, especially in the face of patients who are desperate not to die in hospital, but it is impossible to know how many have received training (Nevé, 2023).

The second public policy recommendation is to implement a national end-of-life evaluation procedure in hospitals, nursing homes, and retirement homes in order to determine the exact state of health democracy on this topic. This assessment of death in France requires a variety of approaches and methodologies.

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Appendices

Appendix 1: Search strategies

Bases in English

Three databases are concerned: Pubmed, Embase and CINAHL. We construct a search equation in three parts: (trusted person) AND (situation leading to the use of the trusted person system: elderly, terminal care, palliative care, coma, etc.) AND (France/French). We apply a filter of date 2002-today if necessary. The search equation for Pubmed is detailed in Section 2.

Embase

Search equation:

('proxy'/exp OR 'proxy consent*':ti,ab,kw OR 'substitute consent*':ti,ab,kw OR 'medical prox*':ti,ab,kw OR 'patient agent*':ti,ab,kw OR 'health care agent*':ti,ab,kw OR 'health care prox*':ti,ab,kw OR 'healthcare agent*':ti,ab,kw OR 'healthcare prox*':ti,ab,kw OR 'trusted person*':ti,ab,kw OR 'trusted people':ti,ab,kw OR 'surrogate decision-mak*':ti,ab,kw OR 'substitute decision-mak*':ti,ab,kw OR 'family decision-mak*':ti,ab,kw OR 'patient representative*':ti,ab,kw OR 'proxy decision-mak*':ti,ab,kw OR 'personne\$ de confiance':tt,oa OR 'substitute\$ judgment\$':ti,ab,kw OR 'surrogate designation':ti,ab,kw OR 'surrogate'/kw OR 'proxy'/kw OR 'kouchner law':ti,ab,kw)

AND ('aged'/exp OR 'elder':ti,ab,kw OR 'aging':ti,ab,kw OR 'aged':ti,ab,kw OR 'frailty'/exp OR 'frail*':ti,ab,kw OR 'palliative therapy'/exp OR 'palliative nursing'/exp OR 'palliati*':ti,ab,kw OR 'terminal care'/exp OR 'terminal care':ti,ab,kw OR 'end of life':ti,ab,kw OR 'intensive care'/exp OR 'intensive care unit'/exp OR 'coma'/exp OR 'critical care':ti,ab,kw OR 'intensive care':ti,ab,kw OR 'coma*':ti,ab,kw OR 'resuscitation*':ti,ab,kw OR 'pseudocoma*':ti,ab,kw OR 'brain death':ti,ab,kw)

AND ('france'/exp OR france:ti,ab,kw,ff,ad,ca OR french:ti,ab,kw OR french:la)

AND [2002-2021]/py

CINAHL Complete

Search equation:

(MH "Proxy" OR AB ("proxy consent*" OR "substitute consent*" OR "medical prox*" OR "patient agent*" OR "health care agent*" OR "health care prox*" OR "healthcare prox*" OR "healthcare agent*" OR "trusted person*" OR "trusted people" OR "surrogate decision-mak*" OR "substitute decision-mak*" OR "family decision-mak*" OR "patient representative*" OR "proxy decision-mak*" OR "substituted judgment*" OR "substitute judgment*" OR "surrogate designation*" OR "substitute designation*" OR "Kouchner law") OR TI ("proxy consent*" OR "substitute consent*" OR "medical prox*" OR "patient agent*" OR "health care agent*" OR

"health care prox*" OR "healthcare prox*" OR "healthcare agent*" OR "trusted person*" OR "trusted people" OR "surrogate decision-mak*" OR "substitute decision-mak*" OR "family decision-mak*" OR "patient representative*" OR "proxy decision-mak*" OR "substituted judgment*" OR "substitute judgment*" OR "surrogate designation*" OR "substitute designation*" OR "Kouchner law") OR SU ("proxy consent*" OR "substitute consent*" OR "medical prox*" OR "patient agent*" OR "health care agent*" OR "health care prox*" OR "healthcare prox*" OR "healthcare agent*" OR "trusted person*" OR "trusted people" OR "surrogate decision-mak*" OR "substitute decision-mak*" OR "family decision-mak*" OR "patient representative*" OR "proxy decision-mak*" OR "substituted judgment*" OR "substitute judgment*" OR "surrogate designation*" OR "substitute designation*" OR "Kouchner law" OR "personne de confiance" OR "personnes de confiance"))

AND (MH ("Frailty Syndrome" OR "Aged+" OR "Terminal Care+" OR "Resuscitation+" OR "Coma" OR "Critical Care+" OR "Critical Care Nursing+") OR AB ("aged" OR "aging" OR "frail*" OR "elder*" OR "palliati*" OR "terminal care" OR "end of life" OR "intensive care" OR "critical care" OR "coma*" OR "pseudocoma*" OR "brain death" OR "resuscitation*") OR TI ("aged" OR "aging" OR "frail*" OR "elder*" OR "palliati*" OR "terminal care" OR "end of life" OR "intensive care" OR "critical care" OR "coma*" OR "pseudocoma*" OR "brain death" OR "resuscitation*") OR SU ("aged" OR "aging" OR "frail*" OR "elder*" OR "palliati*" OR "terminal care" OR "end of life" OR "intensive care" OR "critical care" OR "coma*" OR "pseudocoma*" OR "brain death" OR "resuscitation*"))

AND (MH "France" OR AB ("France" OR "French") OR TI ("France" OR "French") OR AF France OR LA French)

AND DT 2002-

French databases

The databases presented below include articles by French researchers and often refer to the French situation. The model of the search equation used on Pubmed, Embase and CINAHL is used, but the last part on France is removed (because it would be redundant), and the second part is also removed, in order to only query the notion of trusted person on the databases with the least resources or where the search is the most complex.

Banque de données en santé publique (BDSP)

Search equation:

(mc.*:(*"Personne confiance"* OR *"Personne de confiance"*) OR ti.*:(*"Personne confiance"* OR *"Personne de confiance"* OR *"personnes de confiance"* OR *"personne à prévenir"* OR *"personnes à prévenir"* OR *"personne référente"* OR *"personnes référentes"* OR *"tiers de confiance"* OR *"loi Kouchner"*) OR co.*:(*"Personne confiance"* OR *"Personne de confiance"* OR *"personnes de confiance"* OR *"personne à prévenir"* OR *"personnes à prévenir"* OR *"personne référente"* OR *"personnes référentes"* OR *"tiers de confiance"* OR *"loi Kouchner"*) OR re.*:(*"Personne*

confiance" OR "Personne de confiance" OR "personnes de confiance" OR "personne à prévenir" OR "personnes à prévenir" OR "personne référente" OR "personnes référentes" OR "tiers de confiance" OR "loi Kouchner"))

AND (mc.*:("Vulnérabilité" OR "Facteur de vulnérabilité" OR "Fragilité" OR "Personne vulnérable" OR "Soins intensifs" OR "Réanimation" OR "Réanimateur" OR "Réanimation chirurgicale" OR "Réanimation médicale" OR "Coma" OR "Coma dépassé" OR "Etat comateux" OR "Perte de conscience" OR "Syncope" OR "Unité de soins intensifs (USI)" OR "Soins palliatifs" OR "Unité soins palliatifs" OR "Unité de soins palliatifs" OR "Fin vie" OR "Fin de vie" OR "Personne âgée" OR "Troisième âge" OR "Vieillard" OR "Vieillesse") OR ti.*:(vulnérab* OR fragil* OR soins intensifs OR soins critiques OR fin de vie OR palliat* OR coma* OR pseudocoma* OR pseudo-coma* OR réanimation* OR syncope* OR perte de conscience OR personne âgée OR personnes âgées OR troisième âge OR grand âge OR sujet âgé OR sujets âgés OR mort cérébrale OR mort encéphalique OR décès neurologique) OR co.*:(vulnérab* OR fragil* OR soins intensifs OR soins critiques OR fin de vie OR palliat* OR coma* OR pseudocoma* OR pseudo-coma* OR réanimation* OR syncope* OR perte de conscience OR personne âgée OR personnes âgées OR troisième âge OR grand âge OR sujet âgé OR sujets âgés OR mort cérébrale OR mort encéphalique OR décès neurologique) OR re.*:(vulnérab* OR fragil* OR soins intensifs OR soins critiques OR fin de vie OR palliat* OR coma* OR pseudocoma* OR pseudo-coma* OR réanimation* OR syncope* OR perte de conscience OR personne âgée OR personnes âgées OR troisième âge OR grand âge OR sujet âgé OR sujets âgés OR mort cérébrale OR mort encéphalique OR décès neurologique))

Filters :

If applicable, use the Year of Publication filter and check all years after 2002.

ScienceDirect

The English resources available on ScienceDirect can also be found on Embase: we will only use the database to find articles in French (and therefore with French keywords). In the "Title, abstract or author specified keywords" field, enter :

("personne de confiance" OR "personnes de confiance" OR "personne à prévenir" OR "personnes à prévenir" OR "tiers de confiance" OR "personne référente" OR "personnes référentes" OR "loi Kouchner")

On this same menu, it is also possible to fill the Year(s) field with 2002-2021.

CISMEF

Search equation :

(personne de confiance) OU loi Kouchner

Filters :

If necessary, possibility to refine the search with the filters in the left column, selecting all years after 2002.

LISSA

The lack of possibility to search for exact expressions on LISSA and the high number of references found on the site lead to propose a double search strategy to be conducted on the site. The two searches should be conducted together. There are sometimes server bugs on LISSA. Do not hesitate to launch a search twice in a row if it does not give the expected number of results.

The first search is performed using a complex search equation :

((personne de confiance.tl) OU (personnes de confiance.tl) OU (personne à prévenir.tl) OU (personnes à prévenir.tl) OU (tiers de confiance.tl) OU (personne référente.tl) OU (personnes référentes.tl) OU mandataire.mc OU (loi Kouchner.tl))

ET (vulnérab*.tl OU fragil*.tl OU Fragilité.mc OU (soins de réanimation.mc) OU (soins critiques.tl) OU (soins intensifs.tl) OU réanimation*.tl OU syncope*.tl OU (perte de conscience.tl) OU réanimation.mc OU coma.tl OU coma*.mc OU pseudocoma*.tl OU (pseudo-coma*.tl) OU palliat*.tl OU (soins palliatifs.mc) OU (fin de vie.tl) OU (sujet âgé.tl) OU (sujets âgés.tl) OU (sujet âgé.mc) OU (personne âgée.tl) OU (personnes âgées.tl) OU (troisième âge.tl) OU (grand âge.tl) OU (mort cérébrale.tl) OU (mort encéphalique.tl) OU (décès neurologique.tl))

Filters:

In the left-hand "Refine" column, select "Publication Year" and check all boxes from 2002 to 2021.

The second search is based on a simple search equation :

Personne de confiance OU personnes de confiance

Bibliothèque numérique de droit de la santé et d'éthique médicale (BNDS)

The search engine does not seem to support boolean, which limits it to very simple searches.

Search equation 1 :

Personne de confiance

Search equation 2 :

Personnes de confiance

No filters can be applied.

Cairn

Cairn gives a lot of results (some of which are specific to the platform) but without a quality tool to filter, sort or organize these results; moreover, there is no solution to export massively the references.

To the right of the search bar, click on the cogwheel and select "Advanced Search". In the Full text field, write "personnes de confiance" (in the plural, which also finds the singular, whereas the singular expression does not find the plural); then click on the +; select Year of publication; between 2002 and 2021. Check that the two lines are linked by AND. Then add lines dedicated to disciplines: Psychology, Sociology and Society, Public Health, General Interest, Medicine. They all refer to various resources on the trusted person.

A double filter is applied to retrieve the references. We focus on journal articles and we checked only those journals that were not present in another database (notably LISSA and BDSP). We therefore excluded the following journals from the search:

"Cahiers de psychologie clinique, Dialogue, Droit, Santé et Société, Futuribles, Gérontologie et société, Informations sociales, Jusqu'à la mort accompagner la vie : revue de la Fédération JALMALV, Laennec, L'information psychiatrique, Recherche en soins infirmiers, Revue internationale de soins palliatifs, Santé publique, Spirale, Travailler et Vie sociale".

On the other hand, two journals only present on the BDSP (and whose publications are consequently no longer indexed since the end of 2018) have been kept in the search:

"Enfances & Psy et Sciences sociales et santé".

This first filter allowed us to go down to 360 journal articles.

The 360 references were then consulted in order to retain only those references that effectively address the issue of the trusted person as thought by the Kouchner Law of 2002.

SUDOC

Select the advanced search, and choose successively, by making the option "All words": "personne de confiance", "personnes de confiance" et "loi Kouchner".

Filters :

In the advanced search field, select Year of publication and type 2002- (see image above).

Once the search is launched, select the filter Publication type: Thesis (defense version).

Appendix 2: Final corpus

Table 2: List of included studies

Author et al.	Year	Methods	Expe.	Sample size				Structures and context	Geography	Register
				Patients	Trusted persons	Family members	Professionals			
Ait Tadrart et al.	2012	Quanti.	No	150	.	.	.	A geriatric service and an internal medicine service of two hospitals	Paris area	BDSP, LISSA
André et al.	2011	Mixed	Yes	82	.	.	.	Internal medicine service	Paris area	ScienceDirect, LISSA
Azoulay et al.	2003	Quanti.	No	8013	.	.	.	General population survey	National	PubMed, Embase
Basurko et al.	2013	Quanti.	No	257	.	.	167	Services in a hospital in French Guyana	French Guyana	BDSP, ScienceDirect, LISSA
Boyer et al.	2018	Quanti.	No	.	.	.	62	Senior neurosurgeons members of the French Society of Neurosurgery	National	PubMed, Embase, ScienceDirect, LISSA
Degois et al.	2015	Mixed	No	72	.	.	.	A retirement home belonging to an intercommunal hospital, comprising an EHPAD, a long-term care unit, an Alzheimer unit and temporary accommodation.	Burgundy-Franche-Comté region	LISSA, BDSP
Douplat et al.	2019	Quanti.	No	109	.	.	.	Multicenter study in three emergency departments of university hospitals	Rhône-Alpes region	CINAHL, Embase, PubMed
Dumont et al.	2012	Mixed	Yes	.	.	.	28	A geriatric service	Paris area	BDSP, LISSA, Embase, PubMed
Ferrand et al.	2008	Mixed	No	.	.	.	1033	Large multicenter crosssectional study, 1033 departments of 200 hospitals	National	PubMed, Embase

Gignon, Manaouil and Jardé	2008	Mixed	No	125	125	.	.	Services of a university hospital	Hauts-de-France region	ScienceDirect, Embase, PubMed	LISSA,
Guyon et al.	2014	Quanti.	No	241			135	Services of a university hospital	Lorraine region	ScienceDirect, Embase, PubMed	LISSA,
Jouffroy et al.	2014	Quanti.	No	.	.	.	323	Doctors of the Mobile Emergency and Intensive Care Unit throughout France	National	ScienceDirect, LISSA	
Jouffroy et al.	2015	Quanti.	No	.	.	.	36	Physicians and nurses from an out-of-hospital emergency department (Brigade des Sapeurs Pompiers de Paris)	Paris area	PubMed, Embase	
Jouffroy et al.	2017	Quanti.	No				20	Doctors of the Emergency Medical Service in Paris	Paris area	ScienceDirect, Embase	LISSA,
Khetta et al.	2015	Quanti.	No	66	63	.	.	Hospital services for pneumology, digestive oncology, orthopaedic surgery, palliative care and at home as part of a palliative care network.	Normandy region	BDSP, ScienceDirect	LISSA,
Lassalle-Macke and Violeau	2019	Quanti.	No	73	.	.	.	Emergency department	Nouvelle-Aquitaine region	LISSA, ScienceDirect	
Lesieur et al.	2015	Quanti.	No	5589				43 French ICUs (15 units in university-affiliated centers, 28 in general hospitals)	National	PubMed	
Martinez-Tapia et al.	2018	Quanti.	No	236				Cancer patients in a hospital	Paris area	CINAHL, Embase, PubMed	
Molli, Cadec and Myslinski	2007	Quanti.	No	34	9			A sample of 20 people hospitalised in a aged 76 to 94 years (group "A"); a sample of 14 subjects residing in EHPAD, aged 80 to 98 years (group "B"); and a sample of nine relatives, aged 32 to 61 years, designated as "trusted persons" by the hospitalised elderly.	Auvergne-Rhône-Alpes region	LISSA, ScienceDirect	
Nguyen et al.	2017	Quanti.	No	.	169	.	.	19 ICUs (17 in university hospitals)	National	PubMed	

Novella et al.	2006	Quanti.	No	70	127		16 Alzheimer centres, including 7 university hospital centres (14 in France, 1 in Switzerland, and 1 in Belgium). Interviewed patients during home visits, in Day Hospital, or in institutions.	National and international comparison	PubMed, Embase
Paillaud et al.	2007	Quanti.	No	426			3 geriatric units	Paris area	PubMed, Embase, CINAHL
Paillaud et al.	2017	Quanti.	No	133			Comparison of data from two cross-sectional surveys, one conducted in 3 acute geriatrics wards in 2005 and the other conducted in older patients with cancer enrolled in 2013 in the ELderly CAncer PATients [ELCAPA] cohort. Both surveys took place in the same hospital	Paris area	CINAHL, Embase, PubMed
Pavageau et al.	2019	Quali.	No	13		12	General practitioners and outpatients (at home, or in a nursing home or palliative care network).	Occitania region	LISSA, ScienceDirect
Péoc'h and Ceaux	2009	Mixed	No			1770	Cohort of health professionals working in the Toulouse Hospitals	Occitania region	BDSP, LISSA
Perceau et al.	2014	Mixed	Yes	40			Palliative care unit	Auvergne-Rhône-Alpes region	ScienceDirect, LISSA
Quenot et al.	2020	Quanti.	No			87	One mixed ICU in a non-academic general hospital, and one medical ICU in a university teaching hospital	Burgundy-Franche-Comté region and Normandy region	Embase
Rigaud et al.	2016	Quanti.	No			99	One mixed ICU in a non-academic general hospital, and one medical ICU in a university teaching hospital	Burgundy-Franche-Comté region and Normandy region	Embase, PubMed
Roger et al.	2015	Quanti.	No	625			66 southern French ICUs	South of France	PubMed, Embase
Rwabihama et al.	2020	Mixed	No			150	3 tertiary geriatric referral centers	Paris area	CINAHL, Embase, PubMed

Sarradon-Eck al.	et 2016	Quali.	No	6	20		Mobile palliative care unit of a regional cancer centre	Provence-Alpes-Côte d'Azur region	PubMed, Embase, ScienceDirect, LISSA
Trarieux-Signol al.	et 2014	Mixed	No	197			Haematological unit of a university hospital	Nouvelle-Aquitaine region	CINAHL, Embase, PubMed
Velter et al.	2016	Quanti.	No	.	.	34	Dermatooncologists of the French Society of Dermatology	National	PubMed, Embase, ScienceDirect, LISSA
Vinant et al.	2015	Quali.	No	23			Day hospital in an oncology department of a university hospital	Paris area	PubMed, Embase, ScienceDirect, LISSA



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