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## Informal caregivers of elderly patients in France: their behavior as trusted persons and their knowledge of this concept

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## **Informal caregivers of elderly patients in France: their behavior as trusted persons and their knowledge of this concept**

### **Abstract**

*Background: In end-of-life situations, patients frequently lack the ability to make decisions. In France, the trusted person arrangement allows the elderly patients' voices to be heard even after the onset of cognitive decline. The testimony of the trusted person prevails over any other from family and friends.*

*Objective: The aim of our study is to measure the propensity of informal caregivers of elderly patients to be formally designated as a trusted person, their propensity to act as a trusted person without formal designation, their understanding of this concept, as well as factors favouring trusted person behaviour and completion of designation formalities.*

*Methods: We conduct an online survey of informal caregivers of elderly patients, based on a panel of caregivers of patients over 65 years old, residing in metropolitan France.*

*Results: Most informal caregivers act as trusted persons. Formal appointment is not systematically made. Caregivers understand the core missions of trusted third parties, i.e. conveying the patient's medical wishes, accompanying them to consultations and providing advice. Nevertheless, confusion persists, with concepts such as contact person, caregiver and guardian. There is a lack of awareness of the procedures for appointing trusted persons. We find that the hospital is the most effective source of information. Finally, we show that the level of legal knowledge has no significant effect on the behaviors observed, while the intensity of the assistance provided is associated with a greater probability of assuming the role of trusted support person, all other things being equal.*

*Conclusion: The lack of formalization is widespread in our sample, despite the fact that these missions are actually carried out in the field by the majority of caregivers. This raises the question of a possible reform of the system. The external validity of our results must be qualified, however, by the size of our sample.*

**Keywords:** informal care; legal knowledge; trusted person; elderly patient; France

## Introduction

In end-of-life situations, the presence of trusted persons allows to improve the quality of death. Indeed, in France, at the moment of their death, two-third of patients are unconscious. This complicates the treatment choices for the medical team as only about 6.6% of patients had expressed their wishes about no life-prolonging treatment. As a result, only 35% of nurses are satisfied with the quality of their patient's death (Ferrand et al., 2008). The study by Ferrand and coauthors (2008) shows that prior designation of a trusted person improves nurses' perceived quality of death. This highlights the particular importance of the study of trusted persons in France.

As patients frequently lack the ability to make decisions in end-of-life situations, these talks are frequently held among doctors, nurses, and family members or relatives who represent and act as surrogates for the patient's opinions and values (Lesieur et al., 2015; Curtis and Vincent 2010). As stated in Kouchner (2002) and Claeys-Leonetti (2016) regulations reproduced in the Public Health Code ("Code de la santé publique", henceforth "CSP", CSP art. L.1111-6 al. 2), the system of trusted person allows patients to officially appoint a spokesperson through a written procedure. Patients can select a close relative, family member, friend or even their general practitioner. In cases where the patient is unable to interact, the trusted person's primary mission is to express the patient's wishes, values, and preferences to the medical team. With the exception of the advance directives, the testimony of the trusted person then takes precedence over any other testimony.

The trusted person arrangement is of particular interest to elderly patients. First, when triggered by patients and their relatives before cognitive impairments arise, it allows the elderly patients' voices to be heard even after the onset of cognitive decline. Second, when a patient is suffering from an advanced or final stage of an advanced and incurable disease, according to the law (CSP art. L.1111-12), physicians are required to inquire about the expression of the patient's desires. If the doctor cannot discover the patient's preferences through advance directives, the doctor must collect the evidence of a trusted person or, failing that, any other witness from family or close friends. Third, aside from conveying the patient's wishes, the trusted person performs other missions. According to the French legal framework, the trusted person is responsible for accompanying patients to medical visits and counselling the patient on medical decisions. This mission of accompaniment is particularly important for elderly patients who may feel vulnerable in the care process.

According to Faye-Ropaul et al. (2023), when patients identify a trusted person, they prioritize family members, with their spouse ranking top, followed by descendants, other family members, friends, and, in rare cases, 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). Furthermore, when choosing a trusted person, patients look for several characteristics, including connection, emotional closeness, commitment, responsibility and trust. A solid understanding of the patient is also required (Pavageau et al. 2019). Patients also consider practical variables such as geographical closeness, mobility, availability and medical history knowledge (Sarradon-Eck et al., 2016).

These characteristics are similar to those of informal caregivers, causing one to wonder if the primary caregiver is not also the one listed as a trusted person. In retirement homes, at the time of admission, the main caregiver frequently accompanies the senior resident and is designated as the trusted person for the duration of the patient's stay (Faye-Ropaul and Khalil, 2022).

Moreover the French legislation indicates that the elderly person's " relative caregiver " may be " their spouse, the partner with whom they have concluded a civil solidarity pact or their cohabitant, a parent or an ally, defined as family caregivers, or a person living with them or maintaining close and stable ties with them, who helps them, on a regular and frequent basis, in a non-professional capacity, to carry out all or part of the acts or activities of daily living " (Article L. 113-1-3 of the Code de l'action sociale et des familles, henceforth "CASF", taking up Article 51 of the Act of 28 December 2015 on the adaptation of society to ageing (ASV Act)).

Is this very broad legal definition of their role well understood by caregivers? When a caregiver accepts to help an elderly patient, what is the nature of the missions accomplished in the field? Do they not end up assuming the role of trusted person without having been officially appointed?

Four important research questions are therefore included in our work. First, we assess how well elderly patients' informal carers understand the meaning of "trusted person" and the missions that fall under its purview. Second, we measure the proportion of informal caregivers who accomplish the missions of trusted persons. Third, we estimate the proportion of caregivers who accomplish the missions of trusted persons without being formally designated. Finally, we investigate what motivates people to fulfil trusted person missions and formalize the relationship through a written document.

Regarding the drivers of caregivers behaviour as trusted persons, we focus on two key factors of importance. First, the impact of legal knowledge on the choices of informal caregivers. We assume better understanding of the trusted person's rights and responsibilities leads to a greater willingness to adopt and formalize trusted person missions. Second, we measure if a deeper involvement in the caregiving relationship induces a higher propensity to assume and formalize trusted person missions. Indeed, the literature shows that a solid understanding of the patient, geographical closeness, mobility, availability and medical history knowledge are important attributes of a trusted person (Pavageau et al. 2019; Sarradon-Eck et al., 2016).

We conducted an online survey of informal caregivers of elderly patients, based on a panel of caregivers of patients over 65 years old, residing in metropolitan France in May 2022. We administered a knowledge questionnaire on the trusted person system. We also collected data on the variety and intensity of informal assistance provided and the use of the trusted person scheme. We completed this collection by gathering information on the elderly patient being helped (state of health, type of residence, etc.) and sociodemographic data on the caregiver.

Our contributions to the literature are manifold. Our paper contributes to the literature on informal caregivers on two ways. First, informal support is widely used in the care of dependent elderly individuals in European countries (Colombo et al., 2011). In France, informal care is important in the provision of help at home and personal care (Arnault, 2015).

Part of the literature incurs into the links between informal care and caregivers physical and mental health outcomes. The reviews by Bauer and Sousa-Poza (2015) and Bom et al. (2019) indicate that the presence and intensity of these health impacts vary greatly by caregiver subgroup. Caregiving appears to have a negative impact on the health of caregivers, particularly women, married caregivers, and those providing intense care. Those reviews conclude that given the degree of the caregiving effect varies by subgroup; authorities should explicitly target those caregivers who suffer the most negative health consequences from informal caregiving. Although our article does not specifically measure the health impacts of caregivers, we suggest that it is in the public interest to consider trusted persons as a separate subgroup. The specific challenges and issues faced by trusted persons may have particular consequences for the mental health of caregivers and shall be investigated in further studies.

Second, Barnay and Juin (2016) analyze the empirical impact of informal and formal care on patients' mental health while accounting for care endogeneity. Their findings reveal that informal care reduces the risk of depression in dependent older people while formal care improves their overall mental health (as assessed by the Mental-Health Inventory, MHI-5). Our article does not specifically measure the effects of trusted persons on mental health. Nevertheless, our study shows that caregivers predominantly take on two trusted person tasks: accompanying patients to medical visits and counseling. This description of support tasks provides a better understanding of how informal help may contribute to the good mental health of elderly patients.

Our paper contributes to the literature on the knowledge and understanding of law in three ways. Our first contribution to this literature is collecting data on potential trusted persons and their knowledge of the missions of the trusted person. Concerning France and the trusted person system, Faye-Ropaul et al (2023) list a set of papers measuring the level of knowledge of patients, their families and health professionals (André et al., 2011 ; Guyon et al., 2014 ; Ait Tadrart et al., 2012 ; Paillaud et al., 2017 ; Martinez-Tapia et al., 2018 ; Jouffroy et al., 2014; Jouffroy et al., 2015; Jouffroy et al., 2017 ; Rwabihama et al., 2020 ; Khetta et al., 2015 ; Sarradon-Eck et al., 2016 ; Dumont et al., 2012 ; Péoc'h and Ceaux, 2009). However, their scoping review indicates that French research on trusted persons provides little data on the knowledge of trusted persons themselves, compared to data collected on patients and health professionals. We can however point out the paper by Khetta et al. (2015), showing that 56% of the trusted persons reported not knowing the roles that this status gives them (n=35/63). We contribute to the literature by collecting data on potential trusted persons and on their knowledge of the missions of the trusted person provided by the law.

Our second contribution is collecting data on confusions between the trusted person system and other support systems for vulnerable patients. We extend this data collection carried out by the previous papers (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) by questioning the caregivers on the distinction they make between the concept of "trusted person" and other support systems for vulnerable patients, in particular legal protection systems for their assets such as guardianship, curatorship and safeguard of justice.

We also collect data on the sources of informal caregivers' knowledge. According to Quenot et al. (2021), the designation of a surrogate is frequently proposed at the start of the hospital

stay, without any specific procedures, implying that there is no standardized process for delivering information and discussing the role of trusted persons prior to their appointment. This partly explains the poor knowledge of patients and their families on the trusted person system. Our paper completes this literature by collecting data on the origins of caregivers' knowledge of the trusted person system. We also assess whether the hospital, as a source of information, provides a better level of knowledge about the system than other possible sources.

Finally, our paper contributes to the French literature on the topic of trusted person designation rate. Our paper complements this literature, which attempts to measure the rate of designation, by suggesting that the observed rates of designation underestimate the number of persons actually performing trusted person duties. Faye-Ropaul et al. (2023) find that the designation rate of trusted persons varies through time and space, with designation rates well above or below the 50% threshold. Our results show that many caregivers convey the patient's medical preferences, accompany them to doctor's appointments and provide advice in their medical journey, even though no official trusted person designation document has been signed.

The rest of the paper is organized as follows. Section 2 presents the data and estimation strategy. Section 3 describes the results. Finally, section 4 ends the paper with a discussion of our results and some concluding remarks.

## **I. Data and estimation strategy**

### **I.1. Data and sampling**

We present below the main measures of our questionnaire, relating to knowledge of the trusted person scheme, the missions of the trusted persons, the characteristics of the informal help provided, the profile of the caregiver and the senior patient.

The respondents were family caregivers and close caregivers of seniors over 65 years of age. The caregiver is the person who provides non-professional assistance, in part or in full, to a dependent person for the activities of daily living. This help can be provided on a more or less regular basis, for more or less long periods or even permanently. Participants must be over 18 years old and reside in Metropolitan France. Any respondent who did not meet these criteria was excluded from the final database.

We utilized EasyPanel, an online service to access a diverse and representative pool of participants.<sup>1</sup> The survey questionnaire was distributed to a sample from all over France, representative of the French population by cross-sectional sex-ageing.

To ensure accurate identification of informal caregivers, screening questions were embedded inconspicuously at the start of the survey to mitigate response bias and maintain the integrity of the collected data. In particular: *'Click on "yes" if the situation described corresponds to your profile: I regularly help an elderly person over the age of 65 with certain daily tasks. Examples of help: washing, dressing, getting up, going to the toilet, eating, cleaning, preparing meals, managing a budget, taking care of papers, shopping, getting around, etc.'*

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<sup>1</sup> <https://pro.easypanel.fr/access-panels-online/>



Questions are embedded in other unrelated questions to drown out the topic of caregivers amidst other topics, and limit the opportunistic behavior of panel respondents. For example: “Click on “yes” if the situation described corresponds to your profile: I recently acquired some gardening tools.”

Before starting the questionnaire, respondents were provided with legal information about the research project, including the categories of data processed, data protection measures, risks for participants, as well as a reminder of the right to withdraw and RGPD rights. Respondents started the questionnaire after formally giving their consent. This questionnaire has been filed with the Data Protection Officer of Sciences Po Paris.

### **Sample characteristics**

134 participants complete entirely the questionnaire. The caregivers in our sample are predominantly women (56%), in couple (80.6%), with an average age of 51.87 years (see sample characteristics are displayed in Table 1). They are majoritarily employees (66.4%). 34.3% of the caregivers work in the public sector, while others are in the private sector or assimilated. Table 1 also indicates that 17.2% of the respondents work in relation with the medical sector.

Regarding the patients that the caregivers assist, their average age is 81.57 years. Most of them live at home, as only 7.5% are residents of nursing home or long-term care facilities. Regarding their health state, 69.4% have chronic health problems, measured by the question “Do they have a chronic or long-term illness or health problem (e.g. high blood pressure, diabetes, etc.)?”, with possible answers “yes; no; do not know; do not want to answer”. The binary variable *Chronic health prob.* equals 1 if the respondent answers “Yes,” and 0 otherwise.

26.1% have severe physical limitations, measured by the question “Have they been limited for at least six months, because of a health problem, in the activities people usually do?” with possible answers “Yes, severely limited; Yes, limited but not strongly; No, not limited at all; I do not wish to answer”. The binary variable *Highly limited* equals 1 if the respondent answers “Yes, severely limited” and 0 otherwise.

36.6% have generally poor health, measured by the question “How is their general state of health? Do not include temporary or passing problems (flu, broken leg, etc.)” with possible answers “Very good; Good; Fairly good; Poor; Very poor.” The binary variable *Bad general health* equals 1 if the respondent answers “Poor; Very poor” and 0 otherwise.

Regarding caregivers assistance to patients, the average number of daily living tasks for which caregivers provided assistance equals 4.224 (std. dev.: 1.87) out of possible 9 activities (Washing or dressing; Eating or drinking; Cleaning, washing up or doing the laundry; Preparing meals; Managing the budget, taking care of papers; Shopping; Getting up, going to the toilet; Getting around outside; Another activity of daily living.). 17.2% provide financial help. 89.6% provide moral support. 65.7% provide health at least for 1 year and less than 5 years, while 20.1% provide assistance for more than 5 years. Among the caregivers composing our sample, 52.2% help their father or mother.



**Table 1: Sample characteristics**

	Mean	St.Dev	Min.	Max.
Knowledge test – total score	5.657	2.61	0	12
Simple caregiver	.261	.441	0	1
De facto trusted person	.537	.5	0	1
De jure trusted person	.201	.403	0	1
Med. Task 1 (attend consult.)	.639	.482	0	1
Med. Task 2 (access med. Info.)	.565	.498	0	1
Med. Task 3 (express patient's med. wishes)	.545	.5	0	1
Help parent	.522	.501	0	1
Informal care – Nb. Activities	4.224	1.87	1	9
Financial support	.172	.378	0	1
Moral support	.896	.307	0	1
Age patient	81.567	7.845	65	97
Bad general health	.366	.483	0	1
Chronic health prob.	.694	.463	0	1
Highly limited Institution	.261	.441	0	1
Institution	.075	.264	0	1
Less 1 year of care	.142	.35	0	1
1-5 years of care	.657	.477	0	1
+ 5 years of care	.201	.403	0	1
Age	51.873	13.313	24	75
Woman	.56	.498	0	1
Couple	.806	.397	0	1
Medical sector	.172	.378	0	1
Employed	.664	.474	0	1
Unemployed or inactive	.082	.276	0	1
Retired	.254	.437	0	1
Public sector	.343	.477	0	1
Before bac.	.134	.342	0	1
Baccalaureate	.231	.423	0	1
Bachelor and equiv.	.433	.497	0	1
Master, doctorate	.201	.403	0	1

N=134

### **Knowledge test**

We constructed a set of 13 questions to measure the level of knowledge of caregivers and family caregivers about the concept of trusted person. These questions are listed in Table 2. We have included questions regarding the legal definition of the trusted person and the missions provided by law. Thus, we asked respondents about the possible identity of the trusted person (*test1*), the method of designation (*test2*), the differences with other modalities of representation of the elderly patient (*test3* to *test7*), and the list of tasks assigned by law to the trusted person (*test8* to *test13*). Table 2 shows the correct answers in bold for each question asked. We construct a variable called *Knowledge test – total score* by adding up the points

obtained by the respondent for each of the 13 questions (one point per correct answer). We also ask the respondents about the sources of information to which they had access on the trusted person scheme.

As shown in Table 1, the understanding of the concept of trusted person is rather low in our sample of caregivers. Indeed, the average of *Knowledge test – total score* is 5.657 out of 13, with a standard deviation of 2.61.

**Table 2 – List of questions - knowledge test on the concept of trusted person**

Variable	Question	Possible answers
test1	According to the law, who can be the trusted person?	Exclusively a family member, <b>Anyone you want</b> , I don't know
test2	By law, how can the trusted person be designated?	Exclusively verbally, In writing or verbally, <b>Exclusively in writing</b> , I don't know
	We are going to cite several expressions that may or may not be synonymous with "the person of trust". For each term, tell us if, according to the law, the rights and responsibilities are the same as for the "trusted person". Choose the appropriate answer for each item	
test3	Reference person	yes/ <b>no</b> /don't know
test4	Agent for future protection	yes/ <b>no</b> /don't know
test5	Tutor (guardianship)	yes/ <b>no</b> /don't know
test6	Curator (curatorship)	yes/ <b>no</b> /don't know
test7	Safeguard of justice	yes/ <b>no</b> /don't know
	We are going to tell you about several activities. For each of them, tell us if it is an activity of the person of trust provided for by law. Choose the appropriate answer for each item	
test8	Attend medical consultations and interviews, if the patient wishes	<b>yes</b> /no/don't know
test9	Have access to medical information about the patient, unless limited by the patient	<b>yes</b> /no/don't know
test10	To express the patient's wishes and medical wishes	<b>yes</b> /no/don't know
test11	Be legally responsible for the medical decision, when the patient is unable to express his/her wishes	yes/ <b>no</b> /don't know
test12	To ensure the protection of the patient's property (assets, housing, etc.) when the patient is no longer capable of doing so	yes/ <b>no</b> /don't know
test13	To help the patient who has lost his or her autonomy in the tasks of daily life (washing, eating, cleaning, etc.)	yes/ <b>no</b> /don't know
<b>Information source</b>	How did you learn about this trusted person system?	Free text

Note: For each question, we indicate the correct answer in bold.

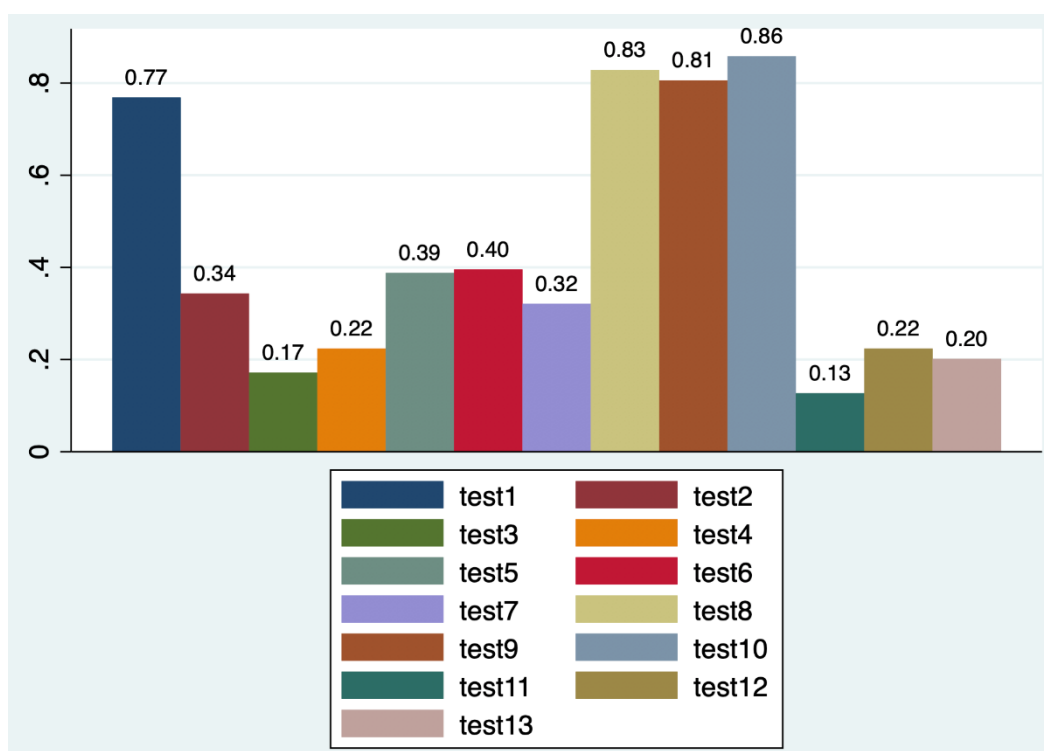
Figure 1 displays the mean score by item from the knowledge test. Overall, the caregivers in our sample have a good knowledge of the possible identities of trusted persons (*test1*) and their core missions (*test8*, *test9*, *test10*), with percentages of good answers above 80%. Caregivers understand that the trusted person can be anyone the patient wants, that the law provides that the trusted person attend medical consultations, have access to medical information unless limited by the patient and express the patient's medical wishes.

However, our test shows that the caregivers lack knowledge on the formalism expected for an official designation (*test2*). Only 34% understand that the designation requires a written document. We notice confusions between the trusted person system and other support systems for vulnerable patients. As in the previous literature, we note that the respondents confuse the concept of trusted persons and reference persons. Only 17% of the respondents understand that the trusted person and the reference person do not have the same rights and responsibilities.

We also assess the distinction that caregivers make between the concept of "trusted person" and other support systems for vulnerable patients, in particular legal protection systems for their assets such as agent for future protection (*test4*), guardianship (*test5*), curatorship (*test6*) and safeguard of justice (*test7*). We also question the caregivers on whether one of the trusted person duties is to ensure the protection of the patient's property (assets, housing, etc.) when the patient is no longer capable of doing so (*test12*). The rates of good answers go from 22% minimum to 40% maximum, indicating the rather low understanding of the distinction between the trusted person system and other support systems for vulnerable patients.

French research on the subject of trusted persons demonstrates how patients and trusted people sometimes confuse the functions of trusted persons and informal caregivers. Patients and trusted persons cite help with daily living activities and provision of healthcare when questioned about the function of the trusted person by their side (Azoulay et al., 2003; Molli, Cadec and Myslinski 2007; Ait Tadrart et al., 2012; Sarradon-Eck et al., 2016; Pavageau et al., 2019). As one of the responsibilities of the trusted person, managing administrative issues is also cited by patients and trusted persons (Ait Tadrart et al., 2012; Pavageau et al., 2019; Rwabihama et al., 2020). We confirm this previous findings with *test13*, measuring whether the respondent believes that 'to help the patient who has lost his or her autonomy in the tasks of daily life (washing, eating, cleaning, etc.)' is one of the duties of the trusted person prescribed by the law. Only 22% of the respondents answer correctly to this question.

Last, caregivers believe that the legal responsibility of the medical decision relies on the trusted person, while the French legal framework states that the responsibility ultimately lies with healthcare professionals. Indeed, only 13% answer correctly to this question (*test11*).

**Figure 1: Mean score by item from the knowledge test**

Those first descriptive statistics lead us to Result 1.

**Result 1:** *In our sample, the possible identities of the trusted person and their principal missions are well known to informal caregivers. The trusted person mechanism is confused with other mechanisms for supporting vulnerable patients and the role of informal caregiver. The formalism of the designation is not understood. The burden of medical responsibility placed on trusted persons is overestimated.*

### **Knowledge sources**

We were also interested in the information sources of participants. We analyse the free text provided by each respondent in question *Information source: 'How did you learn about this trusted person system?'*, and encode the responses. When respondents cite two sources, we assign the first cited source. Figure 2 displays the box plots of *Knowledge test – total score* by information source. The most represented category of information source is “family, friend, word of mouth” with 25.37% of the respondents, followed by the media with 16.42% and the hospital with 14.18%. It can be noted that 14.93% of the respondents did not provide a source of information or answered that they could not remember their point of contact with information on this device.

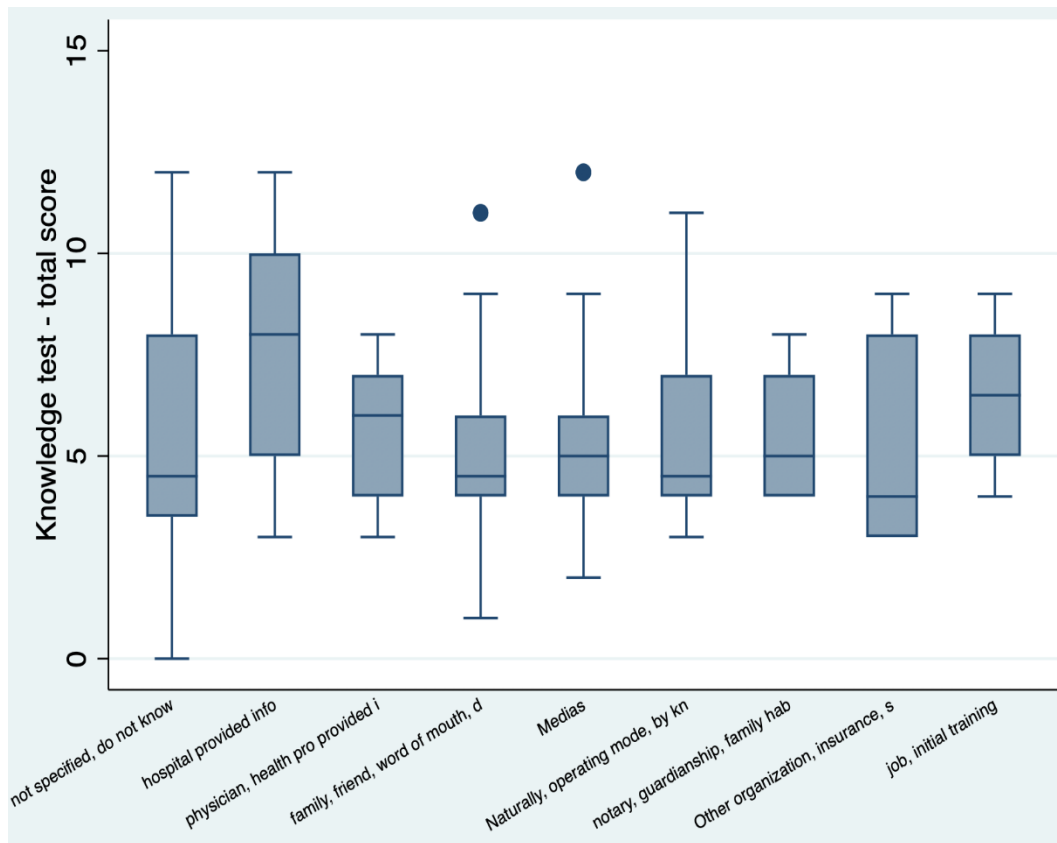
**Figure 2: Box plots of Knowledge test – total score by information source**

Figure 2 shows that the distribution in *Knowledge test – total score* differs between information sources. The degree of knowledge seems higher when information is provided by hospitals, physicians are by initial training. We perform two-sample t-tests to confirm this graphical analysis. The t-tests show that the differences in the means of *Knowledge test – total score* are significant for hospital as source versus others (p-value: 0.0006) and for family, relatives and word of mouth versus others (p-value: 0.0448). We do not find significant results for the other categories.

Table 3 displays how good and bad performers to the knowledge test are dispatched by source of information. The binary variable *Good info.* equals 1 if *Knowledge test – total score* is higher than 6 out of 13, and 0 otherwise.

**Table 3 – Performance to the knowledge test by information source**

	<i>Good Info.</i>		Total
	No	Yes	
not specified, do not	14.61	15.56	14.93
hospital provided inf	7.87	26.67	14.18
physician, health pro	3.37	4.44	3.73
family, friend, word	31.46	13.33	25.37
Medias	19.10	11.11	16.42
Naturally, operating	8.99	8.89	8.96
notary, guardianship,	5.62	4.44	5.22
Other organization, i	4.49	6.67	5.22
job, initial training	4.49	8.89	5.97
<i>Total</i>	100.00	100.00	100.00
<i>Pearson chi2(8) = 13.9105 Pr = 0.084</i>			

We want to determine if performance on the knowledge test may be linked to the source of information. The chi2 test indicates that the hypothesis of independence can be rejected (p-value:0.084). Therefore, there is an association between the source of information and the percentage of good performers to the knowledge test.

For example, when the hospital is the source of information, we compute that 63.16 % of respondents perform well. Only 17.65% of respondents perform well when the information is provided by relatives or friends. Finally, when information is delivered by the media (internet, social networks, television, and press), 22.73% pass the knowledge test.

These descriptive statistics lead to Result 2.

**Result 2:** *In our sample of informal caregivers, the three main sources of information are the hospital, the relatives and the media. The caregivers informed by the hospital are those who, overall, have a better knowledge of the trusted person system.*

### **Categories of caregivers**

We categorize informal caregivers into four groups based on two criteria. The first criterion is concerned with the legality of the designation. We determine whether the caregiver has been formally designated as a trusted person. The second criterion is to determine whether the caregiver, in reality, performs the same tasks as a trusted person.

In order to detect the legal reality of the patient-trusted person relationship, we rely on the question "*Designation modality*". A formal designation is legally valid if the designation was made exclusively in writing or made both in writing and orally. Indeed, French law indicates that the designation is formally valid only if a document has been co-signed by both the patient

and the trusted person. The designation is not valid if the designation was made exclusively orally or that the respondents answer that they « don't know ».

To detect whether the caregiver, in reality, performs the same tasks as a trusted person, we rely on three questions: *Medical\_task1*, where the caregivers indicate whether they '... attend medical consultations and interviews' for the patient they care for; *Medical\_task2*, where they declare whether they '... consult medical file or medical information' of the patient they assist; and *Medical\_task3*, where they indicate whether they '... express the patient's medical wishes and desires'.

The four categories obtained are: (1) *de jure trusted person* - caregivers have been formally designated in writing and in the field they assume the missions of a trusted person; (2) *simple caregiver* - caregivers have not been designated in writing and in the field and they do not assume the duties of a trusted person; (3) *de facto trusted person* - caregivers have not been formally designated at all and in the field they assume the duties of a trusted person; (4) *withdrawn trusted person* - caregivers have been formally designated in writing, but in the field they do not assume any of the missions of a trusted person.

This last configuration - *withdrawn trusted person* - would be quite possible insofar as psychological factors may hinder the effective performance of the trusted person's duties (Faye-Ropaul et al., 2023). Having to represent a loved one or feeling pressured to make difficult decisions can cause the trusted person to experience 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 cause the trusted individual to neglect their obligations and forfeit any position by fully relying on health professionals (Molli, Cadec, and Myslinski 2007). However, in our sample, we do not find any withdrawn trusted person.

**Figure 3: Caregivers categories**

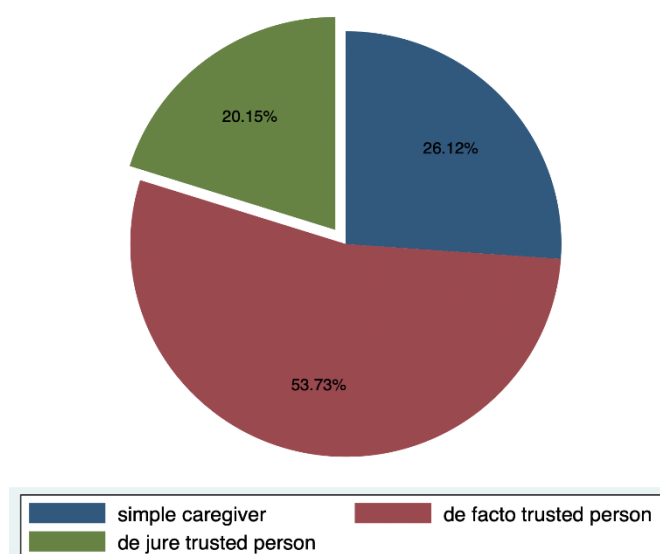




Figure 3 displays the pie chart of caregivers categories from our sample. It shows that half caregivers assume trusted person missions without official designation. Indeed, we have 53.73% of *de facto trusted persons* (N=72/134), 20.15% of *de jure trusted persons* (n=27/134) and 26.12% of simple caregivers (N=35/134).

The one-sample test of proportion  $p=0.5$  for the category *de facto trusted person* gives a p-value of 0.3877, with a 95% confidence interval [0.4528919; 0.6217349], leading us to accept the null hypothesis.

Similarly, the one-sample test of proportion  $p=0.25$  for the *de jure trusted person*  $p=0.25$  gives a p-value of 0.1947 and a 95% confidence interval [0.1335777; 0.2694074], leading us to accept the null hypothesis.

We conclude that the rate of designation of trusted person can be underestimated. In a survey, usually the formal designation would be checked to assign the trusted person role, individuals remaining with patients without formal designation are classified as relatives (Faye-Ropaul et al., 2023). If only 20.15 % of respondents in our sample are formally designated, in reality, the majority of caregivers assume this role. This can also be seen in the free text entered by respondents to question "Information source". Indeed, respondent R121 indicates, for example, that " *I am an only child and I consider myself the trusted person of my mother who lives alone*". We also have respondent R130 who explains that " *it's more a mode of operation that I have with the person I am helping*".

Overall, those descriptive statistics lead us to Result 3.

**Result 3:** *In our sample of informal caregivers, the majority of individuals take on trusted persons missions. Moreover, the majority of individuals who assume the missions of trusted person are not formally designated in writing.*

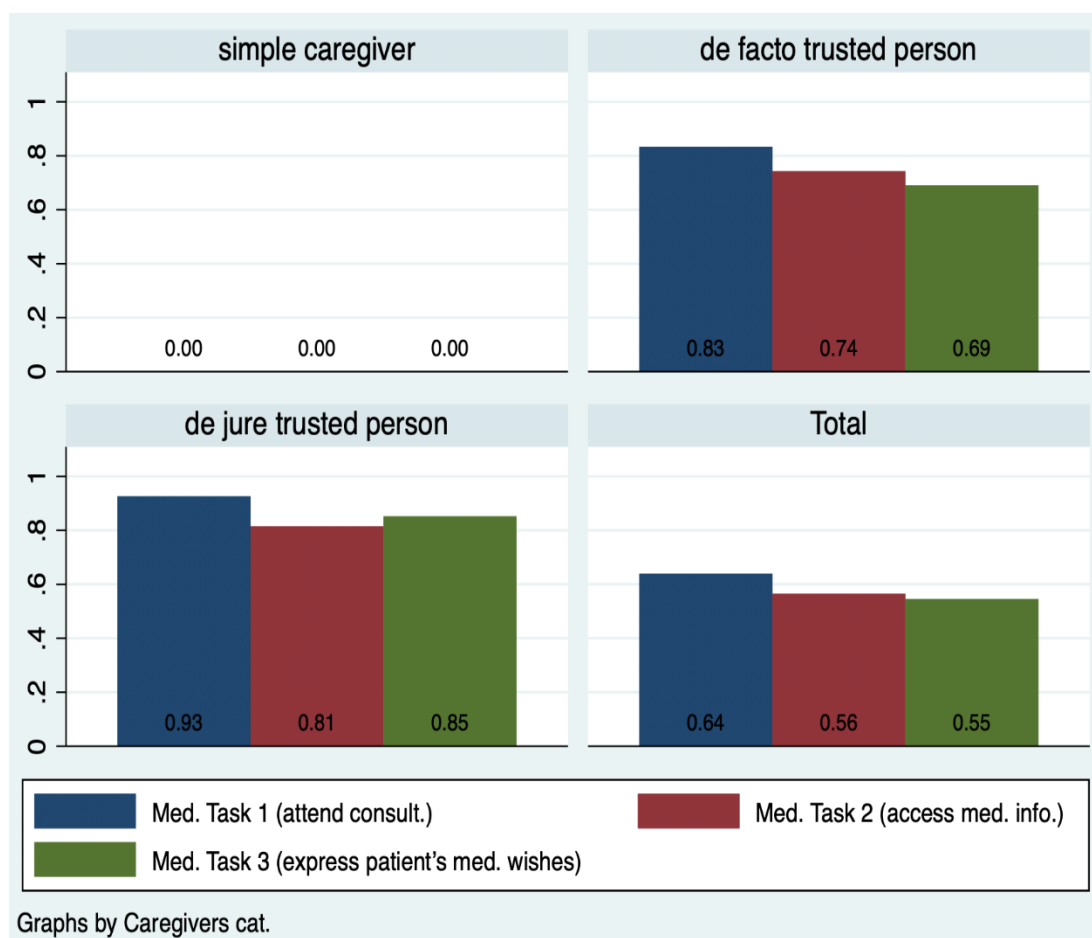
**Figure 4: Core missions of trusted persons by caregivers categories**

Figure 4 displays the percentage of respondents assuming the core missions of trusted persons by caregivers categories. We can observe that simple caregivers do not perform any of the trusted person missions, while the majority of *de facto* and *de jure* trusted persons perform at least one of the three core missions. Our computations indicate that 54.17% of *de facto trusted persons* perform the three core missions, while 66.67% of *de jure trusted persons* assume the three missions. When comparing the proportion of individuals assuming simultaneously the three core missions between *de jure* and *de facto* trusted persons, we do not find any significant difference, with the p-value of the Pearson Chi-2 test equal to 0.262.

Overall, those descriptive statistics lead us to Result 4.

**Result 4:** *In our sample, the proportions of de jure and de facto trusted persons simultaneously assuming the three core missions of trusted persons do not differ.*

## I.2. Estimation strategy

We have a series of observations  $Y_i$  for  $i = 1, \dots, 134$ , of the outcomes of choices for assuming and formalizing trusted persons missions. There are three possible choices: '*simple caregiver*', '*de facto trusted person*' and '*de jure trusted person*'.

We consider two main variables of interest. First, we are interested in the effect of legal knowledge on the choices of the informal caregiver. To capture the knowledge level of individual  $i$ , we primarily use the binary variable *Good info.* (equals 1 if Knowledge test – total score is higher than 6 out of 13, and 0 otherwise). This allows us to capture the variation in probability of choosing option  $j$  given the belonging of an individual to the group of good performers to the knowledge test, in comparison with low performers. We want to measure if a better knowledge of the rights and responsibilities of the trusted person induces a higher propensity to assume and formalize trusted person missions. The second variable of interest is the caregiving relationship. We proxy involvement in the caregiving relationship with the measurements of the type of assistance (*Financial support*, *Moral support*), the intensity of the help provided in the activities of daily living (binary variable *Intensive care*, equal 1 if *Informal care – Nb. Activities* >4 out of 9, equal 0 otherwise), and the length of the caregiving relationship. We also control for whether the caregiver help their father or mother with the binary variable *Help parent*. Other explanatory variables are used as controls. We account for caregivers characteristics and patients profile.

The baseline model is a multinomial probit of the choice of caregiver category (*simple caregiver*, *de facto trusted person* and *de jure trusted person*) on *Good info.*, the caregiving relationship (*Financial support*, *Moral support*, *Intensive care*, *length of care*, *Help parent*) and the control variables.

We provide several robustness checks. First, in the multinomial probit model, we test several specifications for the knowledge level. For instance, we use *test2*, the score for the knowledge question on the formalization of the trusted person relationship. Indeed, knowing that a written document is needed to make the appointment official may have an effect on the propensity to formalize the relationship. We also test for the effect of the information source, with the introduction of *Hospi. Info.* (binary variable equal to 1 if hospital is the information source, 0 otherwise). Indeed, the descriptive statistics show that the information source may influence the knowledge level. We want to test whether the informational context has a specific effect, beyond its correlation with the performance of individuals to the knowledge test.

We also conduct the baseline analysis with a bivariate probit model, where the two binary dependent variables are *Assume missions* (equals 1 if assumes at least one trusted person mission, 0 otherwise) and *Signed document* (equals 1 if a written designation document has been signed, 0 otherwise). This allows us to distinguish differently the choice to assume trusted missions on the one hand and formalization on the other hand.

## II. Regressions

### II.1. Baseline analysis with multinomial probit

We present the marginal effects from the multinomial probit model of the determinants of the choice of assuming trusted persons missions and formalization in Table 4. The estimated probabilities of being a simple caregiver, a de facto trusted person and a de jure trusted person are 26.39%, 53.76%, 19.85% respectively. Characteristics such as the level of knowledge about the system, providing moral support, marital status, belonging to the medical sector,

working in the private or public sector, the patient's general level of health, physical limitations in activities and institutionalization have no significant effect on the choice of alternative between simple caregiver, de facto and de jure trusted person.

In order to understand which factors are statistically significant in the choice to assume the duties of a trusted person, we look at the marginal effects of the 'simple caregiver' alternative. We focus on variables with significance at the 95% or 99% confidence level. At the 95% confidence level, we show that providing financial support activities increases the probability of assuming the role of trusted support person by 25.1%; compared with employees, those who are unemployed or inactive have a 31.6% higher probability. Having a master or doctorate also increases the probability of assuming trusted person missions. At the 99% confidence level, we observe that providing intensive help with daily living activities increases the probability of assuming the role of trusted support person by 19.6%; when the patient has chronic health problems, this increases the probability by 21.2%; each supplementary year in the age of the informal caregiver decreases the probability by 1.3%; compared to employees, being retired increases the probability by 28.3%.

In order to understand which factors are statistically significant in the choice to formalize the trusted person relationship, we look at the marginal effects of the 'de facto trusted person' and 'de jure trusted person' alternatives. We focus on variables with significance at the 95% or 99% confidence level.

At the 95% confidence level, we show that men are 17.8% more likely to formalize the relationship than women. Those who help their father or mother are 13.2% more likely to formalize the relationship, compared with those who help a sibling, partner or other relative; compared with employees, those who are unemployed or inactive have a 28.9% higher probability. Caregivers age decreases the probability to be a 'de facto trusted person'. At the 99% confidence level, we observe that when the patient has chronic health problems, this increases the probability of 'de facto trusted person' by 20.9%.

**Table 4 – Baseline model. Average marginal effects from multinomial probit**

	Pr(simple caregiver)		Pr(de facto TP)		Pr(de jure TP)	
	dP/dx	Std. Err.	dP/dx	Std. Err.	dP/dx	Std. Err.
Good Info.	0.080	(0.067)	-0.059	(0.091)	-0.021	(0.067)
Help parent	-0.109*	(0.064)	-0.023	(0.086)	0.132**	(0.063)
Intensive care	-0.169***	(0.062)	0.053	(0.091)	0.115*	(0.063)
Financial support	-0.251**	(0.124)	0.208	(0.132)	0.042	(0.078)
Moral support	-0.006	(0.111)	0.044	(0.139)	-0.037	(0.092)
Age patient	-0.008*	(0.004)	0.006	(0.006)	0.002	(0.004)
Bad general health	0.082	(0.072)	-0.001	(0.096)	-0.082	(0.071)
Chronic health prob.	-0.212***	(0.071)	0.004	(0.093)	0.209***	(0.068)
Highly limited	0.051	(0.079)	-0.015	(0.103)	-0.036	(0.076)
Institution	-0.136	(0.146)	0.067	(0.169)	0.069	(0.103)
1-5 years of care	-0.157*	(0.090)	0.059	(0.130)	0.098	(0.102)
+ 5 years of care	-0.087	(0.105)	-0.032	(0.159)	0.119	(0.135)
Age	0.013***	(0.003)	-0.010**	(0.005)	-0.003	(0.003)
Woman	0.028	(0.063)	0.150*	(0.088)	-0.178**	(0.070)
Couple	0.029	(0.080)	-0.029	(0.105)	-0.000	(0.073)
Medical sector	0.015	(0.088)	-0.085	(0.119)	0.070	(0.079)
Unemployed or inactive	-0.316**	(0.139)	0.027	(0.169)	0.289**	(0.113)
Retired	-0.283***	(0.102)	0.156	(0.140)	0.127	(0.103)
Public sector	-0.070	(0.073)	-0.034	(0.098)	0.104	(0.069)
Baccalaureate	0.185*	(0.102)	-0.130	(0.142)	-0.055	(0.107)
Bachelor and equiv.	0.015	(0.099)	-0.096	(0.137)	0.080	(0.102)
Master, doctorate	0.235**	(0.111)	-0.120	(0.153)	-0.115	(0.115)

N=134. \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. Robust standard errors in parenthesis. The reference groups are : 'help a sibling, partner or other relative' for the category of patient being helped, 'less than 1 year' for length of care, 'employees' for employment status, 'private sector' and assimilated for employment sector, 'before baccalaureate' for education.

## II.2. Robustness checks with multinomial probit

Table 5 displays the marginal effects after the estimation of the multinomial probit model where the knowledge level is measured by *test2*, the score for the knowledge question on the formalization of the trusted person relationship. Regarding the marginal effects of the 'simple caregiver' alternative, qualitatively we find the same significant effects. Regarding the marginal effects of the 'de jure trusted person' and 'de facto trusted person' choices, we also find similar results, except for the levels of confidence for the variables *Help parent*, and *Baccalaureate*, without consequences on our previous analysis.

Table 5, although providing a new specification of knowledge level, does not provide evidence for a significant effect of legal knowledge on individual choices. Indeed, *test2* is not significant for the three alternatives.

**Table 5 – Average marginal effects from multinomial probit, with knowledge measured by ‘test2’**

	Pr(simple caregiver)		Pr(de facto TP)		Pr(de jure TP)	
	dP/dx	Std. Err.	dP/dx	Std. Err.	dP/dx	Std. Err.
test2	-0.112	(0.072)	0.107	(0.087)	0.005	(0.061)
Help parent	-0.093	(0.064)	-0.033	(0.086)	0.126*	(0.064)
Intensive care	-0.183***	(0.063)	0.069	(0.090)	0.114*	(0.062)
Financial support	-0.286**	(0.120)	0.239*	(0.130)	0.047	(0.077)
Moral support	-0.012	(0.103)	0.054	(0.133)	-0.041	(0.090)
Age patient	-0.007*	(0.004)	0.005	(0.006)	0.003	(0.004)
Bad general health	0.078	(0.070)	0.004	(0.095)	-0.082	(0.072)
Chronic health prob.	-0.208***	(0.069)	-0.004	(0.094)	0.212***	(0.068)
Highly limited	0.064	(0.071)	-0.033	(0.098)	-0.031	(0.075)
Institution	-0.135	(0.134)	0.070	(0.164)	0.065	(0.103)
1-5 years of care	-0.129	(0.085)	0.037	(0.128)	0.092	(0.100)
+ 5 years of care	-0.044	(0.102)	-0.063	(0.152)	0.107	(0.130)
Age	0.012***	(0.003)	-0.009**	(0.005)	-0.003	(0.003)
Woman	0.042	(0.069)	0.132	(0.089)	-0.174**	(0.071)
Couple	0.016	(0.079)	-0.023	(0.106)	0.007	(0.073)
Medical sector	0.035	(0.085)	-0.101	(0.116)	0.066	(0.078)
Unemployed or inactive	-0.304**	(0.141)	0.021	(0.171)	0.283**	(0.113)
Retired	-0.263***	(0.093)	0.136	(0.135)	0.127	(0.102)
Public sector	-0.041	(0.071)	-0.062	(0.097)	0.103	(0.069)
Baccalaureate	0.227**	(0.093)	-0.169	(0.136)	-0.058	(0.107)
Bachelor and equiv.	0.035	(0.097)	-0.113	(0.137)	0.079	(0.105)
Master, doctorate	0.258**	(0.109)	-0.143	(0.152)	-0.115	(0.115)

N=134. \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. Robust standard errors in parenthesis. The reference groups are : ‘help a sibling, partner or other relative’ for the category of patient being helped, ‘less than 1 year’ for length of care, ‘employees’ for employment status, ‘private sector’ and assimilated for employment sector, ‘before baccalaureate’ for education.

Table 6 introduces *Hospi. Info.* and keep *Good Info.* as the proxy for knowledge level. Qualitatively, the results are similar to Table 4 and 5, except for the levels of confidence for the variables *Good Info.*, *Financial support*, *Age patient*, *Woman*, without consequences on our previous analysis. Table 6 allows to test whether the informational context has a specific effect, beyond its correlation with the performance of individuals to the knowledge test. Controlling for knowledge level and other variables of interest, when hospital is the information source, the probability to assume trusted person missions increases by 18.7% at the 95% level of confidence.

**Table 6 – Average marginal effects from multinomial probit, with information source**

	Pr(simple caregiver)		Pr(de facto TP)		Pr(de jure TP)	
	dP/dx	Std. Err.	dP/dx	Std. Err.	dP/dx	Std. Err.
Good Info.	0.124*	(0.065)	-0.092	(0.092)	-0.032	(0.069)
Hospi. Info.	-0.187**	(0.075)	0.145	(0.123)	0.042	(0.105)
Help parent	-0.117*	(0.063)	-0.013	(0.084)	0.130**	(0.062)
Intensive care	-0.164***	(0.061)	0.053	(0.090)	0.112*	(0.064)
Financial support	-0.259**	(0.124)	0.216	(0.132)	0.043	(0.077)
Moral support	0.001	(0.113)	0.038	(0.140)	-0.039	(0.092)
Age patient	-0.008**	(0.004)	0.006	(0.006)	0.002	(0.004)
Bad general health	0.105	(0.073)	-0.019	(0.097)	-0.087	(0.071)
Chronic health prob.	-0.198***	(0.073)	-0.009	(0.094)	0.207***	(0.070)
Highly limited	0.075	(0.077)	-0.036	(0.102)	-0.039	(0.077)
Institution	-0.092	(0.144)	0.039	(0.172)	0.054	(0.108)
1-5 years of care	-0.135	(0.088)	0.044	(0.130)	0.092	(0.102)
+ 5 years of care	-0.072	(0.105)	-0.041	(0.158)	0.114	(0.134)
Age	0.012***	(0.003)	-0.010**	(0.005)	-0.003	(0.003)
Woman	0.054	(0.063)	0.128	(0.088)	-0.182***	(0.070)
Couple	0.024	(0.078)	-0.032	(0.104)	0.008	(0.072)
Medical sector	0.023	(0.085)	-0.091	(0.118)	0.068	(0.080)
Unemployed or inactive	-0.310**	(0.126)	0.026	(0.164)	0.284**	(0.112)
Retired	-0.295***	(0.103)	0.163	(0.140)	0.131	(0.103)
Public sector	-0.078	(0.076)	-0.026	(0.099)	0.104	(0.068)
Baccalaureate	0.181*	(0.099)	-0.129	(0.143)	-0.052	(0.110)
Bachelor and equiv.	0.034	(0.096)	-0.106	(0.136)	0.072	(0.104)
Master, doctorate	0.261**	(0.115)	-0.140	(0.155)	-0.121	(0.117)

N=134. \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. Robust standard errors in parenthesis. The reference groups are : ' help a sibling, parent or other relative' for the category of patient being helped, 'less than 1 year' for length of care, 'employees' for employment status, 'private sector' and assimilated for employment sector, 'before baccalaureate' for education.

### II.3. Baseline analysis with bivariate probit

Table 7 displays the results of the bivariate probit model with the same explanatory variables as in the baseline analysis. Regarding the probability of assuming trusted person missions, employment status (categories: retired, unemployed and inactive) loses in significance in the explanation of assuming trusted person missions, with only 90% level of confidence in Table 7. Financial support and education are no longer significant. Once again, we find that the knowledge level has no significant effect on the caregivers choices. Other variables have qualitative similar results.

Regarding the probability of formalizing the relationship, we find qualitatively similar results in comparison with the baseline model displayed in Table 4.



**Table 7 – Average marginal effects for marginal success probabilities after bivariate probit**

	Assume missions	Signed document
Good Info.	-0.077 (0.066)	-0.017 (0.067)
Help parent	0.106 (0.067)	0.148** (0.065)
Intensive care	0.182** (0.071)	0.127* (0.067)
Financial support	0.198 (0.126)	0.008 (0.090)
Moral support	-0.037 (0.124)	-0.056 (0.107)
Age patient	0.006 (0.005)	0.002 (0.005)
Bad general health	-0.077 (0.082)	-0.076 (0.081)
Chronic health prob	0.227*** (0.070)	0.236*** (0.070)
Highly limited	-0.037 (0.079)	-0.017 (0.077)
Institution	0.164 (0.145)	0.104 (0.095)
1-5 years of care	0.131 (0.094)	0.099 (0.112)
+ 5 years of care	0.027 (0.124)	0.177 (0.150)
Age	-0.011*** (0.003)	-0.003 (0.004)
Woman	-0.028 (0.069)	-0.193*** (0.074)
Couple	-0.015 (0.081)	0.012 (0.081)
Medical sector	-0.017 (0.093)	0.093 (0.080)
Unemployed or inactive	0.266* (0.152)	0.310** (0.124)
Retired	0.208* (0.113)	0.171 (0.111)
Public sector	0.098 (0.071)	0.124* (0.071)
Baccalaureate	-0.165 (0.103)	-0.020 (0.121)
Bachelor and equiv.	-0.030 (0.104)	0.124 (0.119)
Master, doctorate	-0.191 (0.117)	-0.080 (0.131)

N=134. \*\*\* p<0.01, \*\* p<0.05, \* p<0.1. Robust standard errors in parenthesis. The reference groups are: 'help a sibling, partner or other relative' for the category of patient being helped, 'less than 1 year' for length of care, 'employees' for employment status, 'private sector' and assimilated for employment sector, 'before baccalaureate' for education.

The comparison between estimates from Table 4 to 7 yields the following results:

**Result 5 (effect of legal knowledge):** *We find no significant effect of the legal knowledge on assuming and/or formalizing trusted person duties.*

**Result 6 (effect of caregiving relationship):**

- *Those who help their father or mother are more likely to assume and formalize trusted person duties than those who help other members of their family and friends.*
- *Intensively providing informal care in the activities of daily living is positively associated with assuming trusted person duties, but there is only a weak positive effect on formalizing the relationship (90% level of confidence).*
- *Providing financial assistance has a (weakly) positive effect on taking on the role of trusted person, but there is no significant effect on formalizing the relationship.*

**Result 7 (effect of caregivers profile):**

- *Caregivers age decreases the propensity to assume trusted person missions.*
- *Being retired, unemployed or inactive increases the propensity to assume trusted person missions.*
- *Being a man, unemployed or inactive increases the propensity to be a de jure trusted person.*

**Result 8 (effect of patient profile):** *When the patient has chronic health problems, this increases the likelihood of the caregiver assuming the role of trusted person, as well as the likelihood of formalizing the relationship.*

**Result 9 (effect of information source):** *When hospital is the information source on the trusted person system, the probability to assume trusted person missions increases in comparison with other possible information sources.*

## Discussion and concluding remarks

In this paper, we assess the knowledge level of elderly patients' informal carers on the concept of "trusted person". In our sample, we find that informal carers are well aware of the probable identities of the trusted person and their primary missions. We also show that the trusted person mechanism is mixed up with other mechanisms for assisting vulnerable patients, as well as the position of informal caregiver. Informal caregivers do not understand the designation's formality. The load of medical responsibility put on trusted individuals is exaggerated.

This first result suggests that patients' rights and connected legal concepts such as trusted person, informal caregiver and guardianship are not well understood by informal caregivers. We complete the literature on the knowledge level of trusted persons. Faye-Ropaul et al (2023) show that the results are contradictory when it comes to trusted persons' own knowledge of the concept. For instance, according to Khetta et al. (2015), 56% (N=35/63) of trusted persons are unaware of the roles that this position confers. Sarradon-Eck et al. (2016) interviewed 20 trusted persons and discovered that the majority are aware of their spokesperson mission. Nonetheless, the sample size is tiny, and no specific figure is provided. Our data, collected in 2022 on 134 informal caregivers confirm that informal caregivers, as potential trusted persons,

do understand the spokesperson mission, but also the missions of accompaniment and counselling, while they do not master other specificities of the concept.

In our article, we also questioned whether informal carers eventually come to fill the position of a trusted person without having been formally appointed. Therefore, we assess the percentage of caregivers who carry out the duties of a trusted person and the percentage of caregivers who carry out duties as a trusted individual without being formally designated.

We find that the majority of individuals in our sample of informal caregivers take on trusted person missions. Additionally, the majority of informal caregivers who carry out the duties of a trusted person are not legally designated in writing. The shares of *de jure* and *de facto* trusted persons simultaneously carrying out the three basic missions of spokesperson, accompaniment and counselling are similar in our sample.

According to Faye-Ropaul et al. (2023), the designation rate seen in the field varies depending on the study circumstances. Reporting designation rates under 50% are Ait Tadrart et al. (2012), Paillaud et al. (2017), Roger et al. (2015), and Martinez-Tapia et al. (2018). Reporting designation rates above 50% include Basurko et al. (2013), Trarieux-Signol et al. (2014), and Vinant et al. (2015).

Studies measuring the designation rate focus in particular on counting trusted persons formally designated in writing. This has the advantage of highlighting the extent to which this patient right is exercised by patients and their relatives. However, this type of measurement conceals the reality on the ground, as our paper demonstrates. In practice, informal caregivers sometimes carry out the three missions of the trusted person, without the administrative formalities having been respected.

It is understandable that the existence of *de facto* trusted persons is of practical interest to the trio formed by healthcare professional, patient, and caregiver. Presumably, what matters to this trio is that, in the end, information about the patient's preferences is expressed as fluidly as possible to facilitate care; and that the patient feels supported by someone with whom they feel safe, seen and understood.

Although this is not a problem in routine, day-to-day medical care, problems can arise if the patient has to be cared for in an unfamiliar hospital department, or in an end-of-life situation. The written designation confers specific rights that are enforceable against third parties, such as access to medical information (unless expressly specified by the patient) and the primacy of the testimony over any other non-medical testimony (with the exception of advance directives). Failure to make a written designation means that the medical team may not allow privileged access to medical information, and that no primacy may be given to the informal caregiver's testimony. This is presumably particularly damaging to the well-being of both informal caregivers and patients.

Finally, we look into what motivates people to carry out trusted person assignments and formalize the connection with a written document. First, we assess the impact of legal knowledge on the decisions of informal caregivers, assuming that no one can exercise a right about which they are unaware. We examine if a greater awareness of the trusted person's rights and obligations is associated with an increase in the proportions of informal caregivers

participating in and formalizing trusted person missions. We find no significant effect of the caregivers' legal knowledge on assuming and/or formalizing trusted person duties.

Moreover, we collect data on the origins of caregivers' knowledge of the trusted person system. In our sample of informal caregivers, we find that the three main sources of information are the hospital, the relatives, and the media. We find that the caregivers informed by the hospital are those who, overall, have a better knowledge of the trusted person system. We also find that, when hospital is the information source on the trusted person system, the probability to assume trusted person missions increases in comparison with other possible information sources.

This result can be linked to two factors. Firstly, we can assume that the hospital has a better capacity to divulge information on the system: presence of leaflets and posters on the subject, introduction of a designation form accompanied by an information leaflet in the patient's admission file, multiple contacts with professionals likely to raise the subject, etc.

Secondly, we can also assume that informal caregivers first choose the level of assistance, whether or not they wish to accompany patients to medical appointments, and whether or not they are prepared to get involved in administrative paperwork. Then, once in the hospital corridors with the patient, they have access to all the information present within the hospital walls.

Additionally, our study shows that when the patient has chronic health problems, this increases the likelihood of the caregiver assuming the role of trusted person, as well as the likelihood of formalizing the relationship. Regular appointments for the management of health problems may create a higher need for accompaniment at medical consultations. Informal caregivers of patients with chronic health problems may be more likely to find themselves in waiting rooms filled with information or to be incentivized by health professionals to be legally appointed as trusted persons.

This would explain why the hospital is the source of information that gives the best results in the knowledge test and is associated with a higher propensity to assume trusted person missions, and why we obtain no significant effect of the level of knowledge on the behaviors observed. Further fieldwork is required to confirm these interpretative hypotheses.

In this paper, we also assess how the characteristics of the caregiving relationship are associated with the propensity to accept and formalize trusted person missions. We find that those who help their father or mother are more likely to assume and formalize trusted person duties than those who help other members of their family and friends. We also show that intensively providing informal care in the activities of daily living is positively associated with assuming trusted person duties, while there is only a weak positive effect on formalizing the relationship (90% level of confidence). We demonstrate that providing financial assistance has a positive effect on taking on the role of trusted person, but there is no significant effect on formalizing the relationship.

Caregivers who are already deeply involved in the provision of help are also more likely to take on the role of trusted person. This corroborates previous studies in the literature, which explained that qualities of proximity were sought after when appointing trusted persons. However, what our study shows is that the proximity offered by the helping relationship

favours membership of the de facto trusted persons group, without there being any strong correlation with membership of the de jure trusted person group.

We can therefore conclude that there is a certain continuum in the caregiver relationship. There is no real boundary between deeply involved caregivers and de facto trusted persons. This observation raises the question of whether the legal framework should be overhauled. Caregivers can find themselves heartbroken if their special place with the elderly patient is not acknowledged in end-of-life situations.

Finally, we find that being retired, unemployed or inactive is associated with an increase in the propensity to assume trusted person missions. This is quite understandable as the missions of accompaniment and counseling of patients can be time consuming. Data also shows that caregivers age is associated with a decrease in the propensity to assume trusted person missions, while being a man, is associated with an increase in the propensity to be a de jure trusted person. Further studies with sociological and psychological perspectives are necessary to better understand these age and gender effects.

Our study has several limitations. It may be argued that the characteristics of the sample do not correspond to the characteristics of the French caregiver population. This may, for example, limit the scope of results based on averages calculated from the sample.

In addition, the sample may be criticized for being too small (N=134). Nevertheless, it can be seen that in the empirical literature dealing specifically with the trusted person population, as surveyed by Faye-Ropaul et al. (2023), sample sizes are not much larger, but are nevertheless confined to trusted persons present at hospital or hospital service level.

Furthermore, we find no significant effect of the patient living in a nursing home. This may be due by the relatively small number of patients with this characteristic in our sample. We expected a significant positive effect as nursing homes are required by law to disseminate information on the trusted person system upon entry of the patient.

To conclude, our study opens avenues of research. First, data collection on larger and more representative sample is needed to refine results and policy recommendations.

Second, we did not collect information on family composition or potential family conflicts. Roquebert et al. (2018) have, however, shown that family characteristics may influence the children's involvement and care arrangements. Future studies should incorporate broader information on family to confirm our results.

Third, our data are not exhaustive on the patient's profile. We lack information on their knowledge level, their anxiety towards care, etc. One must recall that the trusted person arrangement is similar to a contract involving two parties, the trusted person and the patient. Therefore, to give a better account of why the arrangement remains informal or is formalized with a written document, a joint study of both parties of the contract is necessary.

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