The presence of family and friends at the end of life in French overseas departments

Mathieu Burner[1], Laurent Bubeck[1], Faustine Champain[1], Sophie Pennec[2], Mélanie Lépori[3]

1- EUR Hautes Etudes en Démographie & University of Strasbourg, France
2- Institut national d'études démographiques (INED) France & School of Demography, Australian National University
3- SAGE UMR 7363, University of Strasbourg, France

Short Abstract

Introduction

With more people dying at home in Overseas-France than mainland, the support of family and friends is more important.
We seek to characterise the potential network of care and the one involve during patients' end-of-life.

Data and methods

The data come from the End-of-Life in Overseas-France survey (2022) conducted among doctors who certified deaths using a self-administered questionnaire. A total of 1 815 questionnaires were completed.

We identified the persons present during the last month of life and determined their involvement in the end-of-life care. Specific analyses on cancer patients and people with cognitive disorders were carried out.

Results

The relatives known by physicians are mainly children (74.9% of deceased). A third of patients had a spouse in their immediate circle, and another third had other family members.

The persons the most involved during the last month of life are children and spouses where there was a spouse.

In the event of cognitive impairment, close family relations are more likely to be involved, but looking at each kin separately, the spouse, friends and neighbours are less likely to be present. Those suffering from cancer receive more support than those with another cause of death.

Extended Abstract

Aims

Based on the data from the "End of Life in Overseas Territories" survey (2020-2022), this article aims to characterize the components of the patient's social network and their involvement during the end of life, and to identify certain factors that may influence this presence and involvement during the last month and the last week preceding death. To do this, we identify the social network present during the last month and last week of life for the deceased and assess their involvement in end-of-life care, with a focus on patients who died from cancer and those suffering from cognitive disorders. Indeed, the first hypothesis is to verify whether the presence of the social network is greater in the case of a patient with cancer. Finally, the second hypothesis seeks to determine whether the presence of the social network is lower in the case of a patient with cognitive disorders.

Data and methods

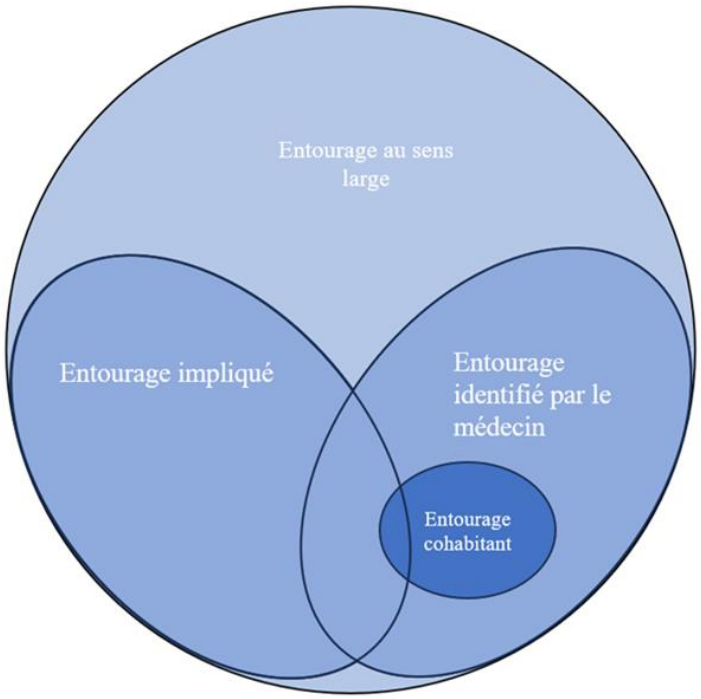
The "End of Life in Overseas Territories" study, conducted from 2020 to 2022, sought to provide an understanding of end-of-life conditions in the four historical overseas French departments.

The study was based on responses from physicians who had certified the deaths of people aged 18 or older between March 2020 and February 2021. These doctors were asked to complete a detailed questionnaire and questionnaire were returned in a manner close to mail-in voting to ensure anonymity for both the deceased and the physicians. The survey was structured into two parts: the first section focused on sociodemographic information about the deceased and the physician; the second covered medical decisions, palliative care, and other details about the end-of-life period.

In total, 1,815 questionnaires were received. A weighting system was applied to adjust for discrepancies in response rates across different territories, ensuring the sample was representative in terms of age, sex, location of death, and timing of death.

The study is based on the description of patients (age, sex, DROM of death), variables concerning the death (place of death, primary cause of death, presence of cognitive disorders), and various variables related to the presence or involvement of the support network. The support network of individuals, as we have defined it here, is broad and includes all people belonging to family, friendship, neighbourly circles, as well as volunteers and religious representatives. In the survey, the support network, its presence, and its involvement are identified through the statements of the physician who responded to the questionnaire. Several types of support networks can thus be considered: the existing support network, which may not be fully known to the physician surveyed; the support network identified by the physician (including those cohabiting with the patient); and among those, the individuals who were actually involved in the care during the last month of life or who visited the person during their last week of life. We have defined the support network in a broad sense to include individuals identified by the physician as part of this network and those involved in the care of the person at the end of life. The cohabiting support network refers to individuals who live with the person at the end of life. We have assumed that all members of the cohabiting support network have been identified by the physician as part of the potential support network (Figure 1).

Figure 1. Detailed description of the support network



Note: entourage au sens large: overall family and friends circle ; entourage impliqué: involved circle; entourage identifié par le médecin: circle dentified by the physician; Entourage cohabitant; cohabiting persons.

Population Characteristics

After filtering out cases of sudden death, the analysis focused on 1,029 responses, offering insights into the characteristics of the individuals who experienced non-sudden deaths. The sample was almost evenly split between men and women (51.8% men, 48.1% women). A large majority of deaths occurred at older ages: only 13.8% of male deaths and 11.4% of female deaths occurred before age 60, while nearly half of male deaths and over 60% of female deaths occurred after age 80 (table 1).

There were notable differences in the place of death between men and women. Men were more likely to die in hospitals, while women were more likely to pass away at home. Nursing homes played a relatively small role, with only around 7% of women and fewer men dying in such facilities. Cancer was identified as the leading cause of death for both men and women, followed by cardiovascular diseases. Around one-third of both men and women had cognitive impairments at the time of death.

Entourage and End-of-Life Care

A key aspect of the study was the role of the deceased's entourage, which included family members, friends, neighbours, volunteers, and religious representatives. The study explored the extent to which these individuals were involved in the care and support of the dying person, especially during the last month of life. Physicians provided information about the deceased's entourage based on their knowledge, including cohabiting family members and those who actively participated in care.

Children, both those living in the same DROM and those residing in other territories, were the most frequently identified members of the deceased's support network. Approximately 75% of deceased individuals had a child present in the DROM, while 54.9% had children living outside their region. In contrast, siblings were less frequently involved, and only about a third of individuals had a spouse in their entourage. When spouses were present, they were almost always involved in caregiving during the final month of life. Non-family members such as friends, neighbours, volunteers, and religious representatives were cited far less often, with volunteers and religious figures being the least involved.

Involvement of the Entourage in the Last Month of Life (table 3)

Most members of the deceased's identified entourage were actively involved in their care during the last month of life. The study highlighted some limitations in the physician's ability to fully identify all members of the deceased's entourage, particularly for children living in other DROMs. In 64.3% of cases, these children were not initially identified as part of the entourage but were later found to have been involved in the patient's care during the last month. Similarly, children living in the same region were overlooked in 21.7% of cases, though they were still involved in care. By comparison, spouses were much more reliably identified and involved, with only 1.6% of cases showing a lack of identification for spouses who played a role in caregiving.

Influence of Cognitive Impairments and Cancer on Care (table 4-5)

Two logistic models were developed to examine whether the presence of cognitive impairments or cancer affected the composition and involvement of the patient's entourage. The first model focused on individuals with cognitive impairments, such as dementia or other neurocognitive disorders. The findings indicated that close family members, particularly children and siblings, were more likely to be involved in care for these individuals. However, spouses were less frequently involved when cognitive impairments were present, and friends and neighbours also played a reduced role in these cases.

The second model looked at patients who had died from cancer. In these instances, the deceased's entourage tended to be more involved compared to other causes of death. Siblings, neighbours, and friends were particularly likely to be engaged in the care of cancer patients during the final month of life.

Conclusion

The "End of Life in Overseas Territories" study provides a comprehensive look at the circumstances surrounding non-sudden deaths in Guadeloupe, Guyana, Martinique, and Réunion. It highlights the importance of family involvement, particularly that of children, in the care of dying individuals, and underscores the role that cognitive impairments and cancer play in shaping caregiving dynamics. While medical professionals and close family members, especially children, were key figures in end-of-life care, the study also pointed out the limited role of nursing homes, volunteers, and religious figures in these regions. Additionally, the findings suggest a strong cultural and familial dimension to caregiving in the DROMs, which warrants further exploration.

By shedding light on the application of end-of-life laws and the role of familial support, this study offers valuable insights for policymakers and healthcare providers aiming to improve end-of-life care in France's overseas territories. Future efforts could focus on improving support for non-family caregivers and addressing the unique challenges faced by individuals with cognitive impairments during the end-of-life period.

Table 1: Characteristics of the deceased population

	Hommes		Femmes		Non renseigné
	n = 530	%	n = 495	%	n = 4
Groupe d'âge					
Moins de 40 ans	13	2,5	10	2,1	-
40 à 59 ans	60	11,3	46	9,3	-
60 à 69 ans	94	17,7	45	9,1	-
70 à 79 ans	107	20,1	89	18,1	-
80 à 89 ans	164	30,9	145	29,3	1
90 ans et plus	90	17,0	155	31,3	-
Non renseigné	2	0,4	4	0,9	3
Département/région du décès					
Guadeloupe	106	20,0	110	22,3	-
Guyane	34	6,5	25	5,0	-
Martinique	154	29,0	132	26,6	-
La Réunion	228	43,1	227	45,8	2
Non renseigné	8	1,5	1	0,3	2
Lieu de décès					
Domicile	184	34,6	252	50,9	3
Etablissement hospitalier	306	57,6	196	39,7	1
Maison de retraite, EHPAD...	28	5,4	35	7,0	-
Autre lieu	6	1,2	10	2,1	-
Non renseigné	6	1,2	1	0,3	-
Cause de décès					
Cancer	192	36,3	155	31,4	1
Maladie cardio-vasculaire	79	14,8	112	22,6	1
Maladie neurologique	84	15,8	97	19,6	2
Maladie infectieuse	78	14,8	54	10,8	-
Maladie de l'appareil respiratoire (hors cancer)	37	7,1	22	4,4	-
Maladie de l'appareil digestif (hors cancer)	19	3,5	13	2,6	-
Troubles mentaux et psychiatriques	11	2,1	18	3,6	-
Mort violente, autre cause	22	4,2	15	3,1	-
Non renseigné	8	1,5	9	1,9	-
Présence de troubles cognitifs					
Pas de troubles cognitifs	235	44,2	196	39,6	1
Troubles cognitifs légers	93	17,5	123	24,8	2
Troubles cognitifs majeurs	178	33,6	159	32,0	1
Ne sait pas	23	4,3	14	2,7	-
Non renseigné	2	0,4	4	0,8	-

Source • Survey FDV en Outre-mer, 2020-2022.
File • non sudden informed deaths of persons aged 18 and over (informed =physican can answer to question about end of life)
Note for reading • 30,9 % deceased men where 80-89 years old.

Tableau 2. Potential family kin of the person at end of life

	Présent		Absent	
	n	%	n	%
Conjoint(e)	355	34,5	674	65,5
Enfant(s) résidant dans le même DOM	771	74,9	258	25,1
Enfant(s) résidant dans un autre DOM	565	54,9	464	45,1
Frère(s)/Sœur(s)	296	28,7	733	71,3
Autres membres de la famille	341	33,1	688	66,9

Source • Survey FDV en Outre-mer, 2020-2022.
File • non sudden informed deaths of persons aged 18 and over (informed =physican can answer to question about end of life)
Note for reading • Among the persons at the end of their life, 34.5 % had a spouse in their potential family network of care.

Tableau 3. Entourage impliqué dans l'accompagnement durant le dernier mois

	Impliqué		Pas impliqué		*car absent de l'entourage*	
	n	%	n	%	n	%
Conjoint/conjointe	310	30,1	719	69,9	674	93,7
Enfant(s)	707	68,7	322	31,3	258	80,1
Frères/sœurs	241	23,4	788	76,6	733	93,0
Autres membres de la famille	310	30,1	719	69,9	688	95,7
Amis, voisins	178	17,3	851	82,7		
Accompagnant bénévole	60	5,8	969	94,2		
Représentant d'une religion	60	5,8	969	94,2		

Source • Survey FDV en Outre-mer, 2020-2022.
File • non sudden informed deaths of persons aged 18 and over
Note for reading • Children were involved in the care during last month in 68,7 % of cases.

Tableau 6. Logistic regression model to investigate the implication of different kin and people in the last month when the person was demented

	n	%	OR	IC à 95 %	p-value
Accompagnement durant le dernier mois					
Entourage familiale proche	452	81,4	4,23	[3,4 ; 5,3]	2E-16
Conjoint(e)	144	25,9	0,69	[0,5 ; 0,9]	0,004
Enfant(s)	390	70,1	1,19	[0,9 ; 1,5]	0,19
Frères/sœurs	126	22,6	0,93	[0,7 ; 1,2]	0,59
Autre(s) membre(s) de la famille	172	30,9	1,12	[0,9 ; 1,4]	0,41
Amis, voisins	81	14,6	0,72	[0,5 ; 0,9]	0,04
Accompagnant bénévole	35	6,3	1,17	[0,7 ; 1,9]	0,51
Représentant religieux	35	6,3	1,17	[0,7 ; 1,9]	0,51

Source • Survey FDV en Outre-mer, 2020-2022.
File • non sudden informed deaths of persons aged 18 and over
Note for reading • Among demented person, 25.9 % had a spouse to care for them during their last month of life
Note • references categories are no dementia and non involvement of the members of the network of care.

Tableau 7. Logistic regression model to investigate the implication of different kin and people in the last month when the person suffered from cancer

	n	%	OR	IC à 95 %	p-value
Accompagnement durant le dernier mois					
Entourage familiale proche	305	87,3	1,5	[1,1 ; 2,1]	0,02
Conjoint(e)	132	37,9	1,6	[1,3 ; 2,1]	2,00E-04
Enfant(s)	242	69,3	0,9	[0,7 ; 1,3]	0,89
Frères/sœurs	118	33,9	2,2	[1,7 ; 2,9]	4,60E-08
Autre(s) membre(s) de la famille	115	33,0	1,3	[0,9 ; 1,7]	0,06
Amis, voisins	87	24,9	2,1	[1,5 ; 2,9]	1,12E-05
Accompagnant bénévole	27	7,8	1,5	[0,9 ; 2,5]	0,08
Représentant religieux	27	7,8	1,5	[0,9 ; 2,5]	0,08

Source • Survey FDV en Outre-mer, 2020-2022.
File • non sudden informed deaths of persons aged 18 and over
Lecture • Among persons died of cancer, 37.9 % had their spouse involved in their caring during their last month of life.
Note • References are not dying of cancer and no involvement of the members of the network of care.