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MODALITIES OF END-OF-LIFE CARE SERVICES IN FRANCE: BETWEEN IMPERATIVE OF PROVIDING PHYSICAL AND PSYCHOLOGICAL COMFORT AND ECONOMIC RESTRICTIONS.

AN ANALYSIS OF STRENGTHS AND WEAKNESSES OF DIFFERENT MODALITIES OF CARE SERVICES IN FRANCE.

This contribution is based on a conducted qualitative survey grounded in systematic observations and thirty interviews with medical staff members, patients, volunteers and patient relatives.

Introduction

End-of-life care is unevenly available in France and varies according to the region, the department, the pathology and its type of care, as well as the income of the concerned individual. To date, dying patients are more likely to benefit from palliative care adapted to their situation, not at home, but in specialized facilities in urbanized regions like Ile-de-France (where Paris is). Despite the French government's effort to develop palliative care between 2008 and 2012, rural regions in central France still fail to meet the demand. Since the beginning of the XXIth century, palliative home care has tended to progressively grow. Yet, a majority is still carried out in palliative care units (PCUs), or more generally, in hospitals. People in their final year of life thus have to travel back and forth between hospital and home.

Demographic ageing in Europe, like in Japan, has become a major economic challenge. Keeping elderly persons or seniors at the end of their lives at home is a solution often put forward to limit current health expenditure and to guarantee the sustainability of the French social security system. Yet, the configuration of health care provision on French territory do not allow people to end their days at home. The aim of this paper is to review the benefits and limits of Hospitalization at Home (HAH).

The end of life is characterized by more or less painful phases varying according to the type of pathology affecting the individual. The law of 9 June 1999 guarantees the right to access palliative treatments to all. Yet, we shall see that only a restricted section of the French population has access to it. In that sense, even if curative treatments stop, home care can prove to be complex, if not impossible, for relatives as much as for patients themselves.

Where do People Die in France?

It was during the XXth century, under the influence of both World Wars, that western medicine made significant progress in terms of skills and expertise. In France, medicine evolved and focused on curative care exclusively. Its rise allowed for the experimentation of new treatment protocols and gave generations of medical staff the hope to bring the deadliest afflictions to an end. In many ways, patients who have experienced therapeutic failure symbolize the inability of the members of the medical staff to save lives. When the medical prognosis turns out to be tragic, the concerned patient is subjected to rejection: he is put in a room, most of the time alone, sometimes hidden behind a screen, as if removed from the living. Patients who are at the end of their lives thus do not receive any special attention from hospital workers: they are those for whom the medical staff "cannot do anything anymore," they are not dead but they are already no longer part of the living. However, they are not sent home, they are kept in hospitals until their actual death.

Death, until the fifties essentially a family affair, would mainly occur at home. Since the end of the XXth century, patients have been facing a medicalised and lonely death, which increasingly occurred in hospitals. Historian P. Ariès notes in this regard a "ban on death" in public spaces, which, he says, appeared between the thirties and the fifties.[1] This time period is a turning point concerning where people die. From the thirties onward, death became medicalised, and by the fifties, people died more and more in hospitals.

Since the end of the XXth century, the French state has registered 540 000 deaths on average every year, 66% of which occurred in an facility.[2] According to a survey published in 2011, 58% of patients who were at the end of their lives died in a hospital, compared with only 26,5% at home.[3] More precisely, one month before death, only 30% of patients were staying in a hospital. In contrast, one day before death, twice as many patients, that is to say 60%, were given care in a hospital. This survey highlights an intensification of patients going back and forth between home and hospital as those individuals grow closer to their death.

However, the increased medicalisation of the end of life is subjected to many criticisms. Still today, the majority of French people is worried about the lack of social and psychological support when having to deal with death in hospitals. Moreover, over-medicalisation of the last phase of life, the ensuing extreme therapeutic efforts, as well as the rejection of the patient's wish to stop therapy have received negative press. In 2009, no less than 80% of French people stated they wanted to die at home. Despite this general consensus, hospital death rates keep growing. Indeed, the last

[1]Ariès, P. *Essai sur l'histoire de la mort en Occident. Du Moyen Age à nos jours*. Editions du Seuil, 1975. Print.

[2]National Observatory for End-of-life Care, « Fin de vie et précarités », *Report 2014*. Print.

[3]Those numbers were taken from a survey led between 1990 and 2008 and commissioned by the National Observatory for End-of-Life Care.

phase of life can prove to be particularly painful physically, especially when the initial cause of death happens to be cancer.

The Unequal Availability of Palliative Care in France does not Meet the Need of the Population

In France and Europe alike, cancer has been the most common cause of death for more than 20 years. The pain caused by this illness is progressive. Palliative care aims at reducing the symptoms and pain which make patients uncomfortable. This kind of care was developed in England, then in Canada in the sixties. Yet, it was not until the eighties that France imported it. The logic of palliative care is to "*do everything that is left to do, when nothing else is left to do*," and mostly concerns patients whose disease is not responsive to curative treatment. While ensuring comprehensive care, including the patient's physical, psychological and social needs, this type of care was a response to the fear of passing away disgracefully caused by an all-powerful medicine which would contribute to the *desocialisation* of the end of life. Yet, this type of care is still essentially provided in hospitals today.

Since the beginning of the XXth century, mobile palliative care teams (MPCTs) and palliative care networks have been developed to provide support to the dying in nursing homes, long-term care units, as well as at home. However, a report from the French National Consultative Ethics Committee published in 2014 shows that the assessment of the palliative care development plan does not meet the growing need of the population. To this day, it has been estimated that there are between 150 000 and 200 000 patients whose conditions require palliative care, yet "*only 20% of those who should benefit from it can access it, and that only with great regional inequalities relating, for instance, to the number of palliative care facilities, or of hospital beds available*."[4] According to this report, one quarter of patients who are at the end of their lives were experiencing real physical discomfort during the last week of their lives, and 7% reported intense pain during the last 24 hours before death. It should also be pointed out that, in addition to this alarming observation, only 71% of beds in Palliative Care Units (PCUs) are located in 5 out of the 26 French regions. And yet those regions only account for 42% of the deaths in the country and 48% of the population concerned with this type of care. Moreover, the report underlines that "in the end, palliative care was less developed at home."[5] Indeed, only 8% of nursing homes call on hospitalization at home for end of life issues. Instead of favoring the stabilization of painful situations at home, patients have to leave their house for urgent care and end up quite often in emergency units. A report published in 2013 by the National Observatory for End-of-life Care underlines that more than 13 000 persons coming from

[4]French National Consultative Ethics Committee, Rapport du CCNE sur le débat public concernant la fin de vie, *Report*. 2014. Print. For more informations about that point, see also Aubry R., "Etat des lieux du développement des soins palliatifs en France en 2010", *Report for the Prime Miniter*, April 2011, p.7.

[5]*Ibid*.: 12.

nursing homes, aged 75 or above, die in emergency units every year.[6] When admitted to those units, more than a third of them go through intensive care when their conditions entitle them to palliative care.

In regard to this quantified analysis, it becomes clear that access to palliative care, even though it has been a right for all embedded in law since the end of the XXth century, is not guaranteed in France. On the one hand, the right to access this type of care is not very well known to the general public. On the other, training in palliative care still is a specialty in medical studies. In other words, only doctors who have chosen to specialize in palliative care are trained for it. Moreover, as we saw earlier on, this type of care is practically unavailable at home. However, the lack of development in palliative care other than in specialized hospitals is not the only impediment to keeping the dying stay at home.

Hospitalization at Home (HAH): History and Operational Aspects

The idea of home care was first developed in the United States following the initiatives by Professor Bluestone as early as 1947. The first French Hospitalization at Home programs were created in the middle of the XXth century, but they really started with the hospital reform law of 1991 and the ensuing implementing decrees of October 1992. HAH is defined as an alternative to hospitalization[7]: "*HAH structures ensure that patients receive constant and the required coordinated medical and paramedical care at home, for a limited period of time which, however, maybe reviewed according to their health status. This type of care differs from the customary home care as it is more complex and more frequent*".[8] HAH programs are thus essentially designed for patients suffering from serious acute and/or chronic pathologies.

In France, surveys reviewing end-of-life home care are scarce. Between 1999 and 2000, the ministry of health ran a national survey on HAH, commissioned by the French Hospital Directory and Health care Organization[9] which showed that, at the end of the XXth century, HAH structures only provide 0,8% of all French hospital capacity. Despite its fifty-year-old establishment, HAH services are still unevenly available in France today (as they are mainly located around Paris and other urbanized areas). Faced with this situation, the Region Scheme for Sanitary Organization was forced to

[6]National Observatory for End-of-life Care. "Fin de vie des personnes âgées", *Report*. 2013. Print.

[7]Magnet, M. and C. Hullen. "L'évolution de l'hospitalisation à domicile en France" Trans. *Oncologie Vol 8.* (2006). Print.

[8]France Health Ministry. Circular DHOS/O n° 2004-44. *On HAH*. 4 february 2004. Print.

[9] Aligon A., Com-Ruelle L., Renaud T.*, «* Evaluation du coût de la prise en charge globale en hospitalisation à domicile », *CREDES*, biblio n°1484, 2003. Print. And for more informations about that subject : Aligon A., Com-Ruelle L., Renaud T., « Le cout de la prise en charge en hospitalisation à domicile (HAD) », *Bulletin d'information en économie de la santé*, n°67, Juin 2003. Print.

develop alternatives to hospitalization as early as 2003, including HAH[10]. In 1999, 52 French departments had no HAH and in 2006 ten departments still had none. Despite this rapid growth, French HAH structures only had 67 000 beds in 2006. In 2012, HAH represented no more than 0,56% of hospital stays.[11]

However, this sort of care represents an interesting alternative to hospital care for patients. Indeed, one of the declared aims is "*to shorten, delay or totally avoid a complete hospitalization, depending on whether patients are directly admitted at home or whether they are transferred to a health establishment, public or private*"[12]. HAH respects most of the patients' wish to die at home while avoiding the inappropriate transport of patients to hospitals. In more concrete terms, almost four out of five hospitalizations first carried out at home avoid standard hospitalizations, hence maximizing the appropriate health care as well as the patients' comfort. Besides, geographical distance and limited time for visits are avoided thanks to a more flexible organization of HAH.

The Development of HAH: A Necessity for Cancer-stricken and/or Dying Patients?

In 2013, palliative care was the number one activity of HAH (one quarter of its activities). By adding chemotherapy administration and post-chemo supervision to palliative care, they account all together for almost 31% of its activities. It is to be noted that in 2013 one third of the patients who were admitted in HAH suffered from a cancerous type of pathology.[13] If cancers represent the first cause of death in France, those pathologies also concern a greater proportion of older persons. In 2011, it was estimated that there were 211 743 new cases of cancer among people aged 65 or above, or almost 58% of cancers estimated for all ages. Similarly, cancers are the deadliest for those more advanced in ages. 72% of all cancer deaths in France thus occurred among people aged 65 or above.[14] To cope with this emergency, the French National Authority for Health intends to support the development of

[10]Sentilhes-Monkam, A. « Rétrospective de l'hospitalisation à domicile », *Revue française des affaires sociales,* n°3, 2005. Print.

[11]Ministry of Social Affairs and Health, *Circulaire relative au positionnement et au développement de l'hospitalisation à domicile*, N°DGOS/R4/2013/398, 4 Décembre 2013. Print.

[12]*Afrite, A., M. Chaleix, L. Com-Ruelle and H. Valdelièvre.* "L'hospitalisation à domicile, une prise en charge qui s'adresse à tous les patients. Exploitation des données du PMSI HAD 2006 *», Question d'économie de la santé,* n°140 March 2009, p. 7. Print.

[13]National Observatory for End-of-life Care, "*La fin de vie des patients hospitalisés à domicile: HAD, fin de vie et précarités »,* Report, February 2015. Print.

[14]National Cancer Institute *« Incidence, mortalité et survie des cancers chez les personnes âgées de 65 ans et plus »,* 2015. Print.

chemotherapy administration at home and will publish a report along these lines during 2015.

Since 1945,[15] life expectancy in Europe has significantly increased. According to recent data published by the French National Institute for Statistics and Economic Studies – INSEE - men can hope to live 78,7 years and women 85 years on average. Life expectancy for healthy 65 year-olds grows less rapidly than life expectancy at birth: that is 9,7 years for men and 9,9 years for women. In 2005, in France, one person out of five is aged 60 or above. According to the predictions of INSEE for the year 2050, no less than one person out of three will be aged 60 or above of a French population that will reach 70 million inhabitants. Those predictions are all the more alarming since the share of labor force among the total population will decrease, yet it is essentially this labor force which finances the French Social Security System through the payment of social contributions and taxes.

Finally, it should be noted that the after-war period is characterized by an average national birth rate above the average which continued until the middle of the seventies. This period was referred to as "baby-boom" and the "baby-boomers" are now at retirement age. By 2030-2045, INSEE predicts a rise of 160 000 deaths every year in France. The ageing of the French population is unavoidable.

The cancer rate is significantly rising with older age, the French population is ageing, the great majority of health care expenses is spent in the last twenty years of life and the consumption of care and medical goods peaks in the last year of life: those are the many variables explaining why the French National Authority for Health is urging to develop HAH in the country.

HAH: A Solution to Limit Current Health Expenditure?

Home care represents a source of important cost savings which could contribute to limit health expenditure. In France, the general social security scheme has been in constant deficit since 2002. 2010 posted a record deficit of 23,9 billion euros which has tended to decrease ever since and dropped below 10 billion euros in 2014. The economic crisis of 2008 which hit most European countries and triggered a decrease of the total wages is one of the main reasons behind such a deficit. The ageing of the population in the medium-term is likewise a cause for substantial concern. In fact, the consumption of care and medical goods in the final year of life costs an average of 20 000 euros per person. It is to be noted that the average consumption of care and medical goods per year and person at any age rises to 2 724 euros.

The average cost of health care through hospitalization at home for a person requiring end-of-life care has been estimate to be at 198 euros per day. The cost of HAH care for medical acts not intended for dying patients amounts to on average to 140 euros per day, 70% of which are spent for direct medical costs (that is medical treatment

[15]This date marks the end of the Second World War as well as the creation of the French social security system.

provided to the patients).[16] Yet the daily average cost of a standard hospitalization comes close to 700 euros. It is obvious that the reimbursement of medical acts and of material, done by the social security is much more attractive with HAH. The most expensive HAH stays are those for ill and/or elderly persons requiring palliative care and whose situations constitute therapeutic failures. Those stays however remain much more expensive in specialized structures or hospitals. Indeed, staying between four and twelve days in a palliative care unit costs on average of 546 euros per day. Palliative care units are mainly structures outside of hospitals. On the other hand, there are internal structures inside hospitals, like designated palliative care bed wards. In those wards, one bed is paid 474 euros per day for the same length of stay. Non-designated beds get the lowest financing with 364 euros per day in 2015. Those beds are generally taken care of by a mobile palliative care team: they are most often found in hospitals, post-operative and rehabilitation services.

Cost-savings realized by the healthcare system can be explained on one hand by ending the most expensive medical acts and, on the other, by increasing the amount left for the households to pay. Indeed HAH does not support certain expensive medical acts covered by hospitals, like costly diagnostics and therapies, as well as costs related to the technical platform profiting from cutting-edge technology.

Moreover, HAH would also reduce the average length of hospital stays. Because the generalization of HAH services in France allows patients to be followed-up by their general practitioners at home, each HAH hospital stay means there are more available beds in hospitals: "*by accelerating the patient turn-over in hospital beds, HAH gives the opportunity to reserve a highly specific equipment for the largest possible number of severely ill patients*"[17]. Shortening of the average length of hospital stay thus allows for the release of patients as soon as their conditions have stabilized. When discharged, they either return home or, if their physical and/or social condition requires it, they are transferred to post-operative and rehabilitation services, nursing homes, long-term care units, medical-social centers, etc. As soon as patients are discharged from hospitals, doctors bring another patient in. Thus, the faster patients leave care facilities, the more hospital activity increases. Generating new hospital stays triggers new revenues, financed by the Social Security so that new patients can be admitted to the concerned hospitals. It is to be understood that the more care facilities maximize new patient admissions, the more their revenues increase which, in the long-term, helps ensure financial balance[18].

[16]The remaining 30% are spent for the medico-social coordination and the running costs of the structures. For more information, see Aligon, A., L. Com-Ruelle and T. Renaud. "Le coût de prise en charge en hospitalisation à domicile (HAD)", *Question d'économie de la santé* n°67 (June 2003). Print.

[17]Lataste, M. "Le projet d'hospitalisation à domicile : application à l'Aquitaine" *Bulletin Société de Pharmacie de Bordeaux n°136* (1997), p. 113. Print.

[18] For more informations about that subject, see also : Pain A., « La DMS, c'est l'affaire de tous », *Hospital Finances*, n°61, Septembre 2012.

To Conclude:

Review of the Benefits and Limits of Hospitalization at Home (HAH) in France

As we could see, HAH represents a source of substantial savings for the French Social Security, and this is even more important since the system is in deficit. But more important than being a source of savings, HAH responds to the growing demand in palliative care for an ageing population who is increasingly struck by cancer. Besides, keeping dying and/or elderly people at home avoids back-and-forth traveling between two structures which, in addition to being expensive, is significantly more uncomfortable for fragile patients in pain. HAH care contributes to reduce "*the risks of developing or worsening a state of physical and psychological dependence and becoming bedridden*"[19].

As we saw earlier on, access to palliative care is a right for all, embedded in law, and yet it is not always guaranteed depending on the region or department of residence. For many patients, palliative care is carried out late, notably because waiting lists for admission to those services are relatively long. Certain patients are thus admitted to those services, having experienced sometimes more than three months of discomfort, surrounded by tired and worried relatives. If developing palliative care structures is costly, HAH represents an interesting solution to cover the whole French territory, specifically in the most rural areas, to guarantee access for all to palliative care and prevent the exhaustion of relatives.

Yet HAH care does not only come with benefits. As we saw earlier on, the development of this modality of health care is unevenly available in France. This late development is cause for a series of limits. Indeed, according to a survey led by the National Observatory for End-of-life Care among a hundred of HAH structures, 76% of them refuse to carry out care work if the patient's home is outside the usual intervention zone. It is to be noted that the further away the patient's home is from the intervention zone, the longer it will take to intervene in case of emergency. In case of intervention in so-called "unconventional" situations, solutions must be found to ensure optimal security at the patients' home. Yet the survey reveals that the more patients live in precarious situations, the higher the risk to be denied HAH care. Indeed 55% of surveyed structures declared they refuse intervention if there is no electricity, running water and/or heating at the patients' home. Likewise, more than half of the structures refused to carry out care work if they had no general practitioner. Finally, HAH care is particularly complex and can be denied if patients live alone.

Providing support at home for persons at the end of their lives essentially implies carrying out health care for elderly persons. Yet seniors are also the most affected by isolation and poverty. Moreover, it is important to note that in 2015, the minimum

[19]Cited by Lataste M., « Le projet d'hospitalisation à domicile : application à l'Aquitaine », Bulletin Société de Pharmacie de Bordeaux n°136 (1997), p.112. In Com-Ruelle L., Raffy N., Quel avenir pour l'hospitalisation à domicile ? *CREDES*, Janvier 1994.

pension amounts to 800 euros per month and the average retirement pension in 2015 to 1288 euros. Since the beginning of the XXIth century, elderly people are increasingly hit by poverty. According to the Observatory for Inequalities, the poverty rate among persons aged above 60 rose from 3,7% to 4,2% between 2000 and 2010. We quickly realize that if more and more elderly persons are in precarious situations, HAH structures will face additional obstacles to carry out the appropriate health care for this group age.

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