

Family caregivers of demented elderly people and access to medical care: Who gets worn out, why and what for?*

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ABSTRACT

Demented persons in the process of slowly becoming dependent have to rely on the assistance of others. These others are health professionals (formal care), on the one hand and family carers (informal care) on the other hand. The latter, whether or not they have chosen to play a role which is hardly defined officially, have to face many difficult situations such as complicated access to care due to lack of equal opportunities under the health system, unable to support them efficiently. Taking care of a demented patient is a life challenge often leading to burn out, having impact on physical and mental health. Caregivers may thus even have no time or opportunity to take care of their own health. So, is it not high time for the decision-makers to think it over and take care of the carers by setting up programs and giving them the opportunity to learn, to work as a team with the professionals so as to protect themselves and their dignity as well as that of their patients. The difficulties/problems carers of demented patients may encounter should be a major issue for public health care because their role is a vital one and because the consequences which may have on their own health can be negative.

Keywords: Dementia; Family; Caregiver; Medical Care Access; Dignity; Health

1. INTRODUCTION

Carers quite often have to deal with professionals and institutions. As their roles are not clearly defined, this can lead, strictly speaking, to difficulties triggering problematic and unprepared situations among the nursing staff. This is particularly true with regard to dependency of

elderly demented persons. Alzheimer's disease or related diseases mobilize the carers. They have to cope with a heavy physical as well as psychological dependency, linked to Behavioural and Psychological Symptoms of Dementia (BSPD) [1-3]. The main carer, usually a member of the family, says it takes him/her between five and seventeen and a half hours a day to take care of the demented person and without having been given any technical guidelines [2,4]. Dementia caregivers spend significantly more hours per week providing care than non-dementia caregivers. They also report greater impacts in terms of employment complications, caregiver strain, mental and physical health problems, leisure-time. [5]

Telling them "do your best" gives main care-givers an illusion of freedom when efficiency is missing. "The role of the family carers is the one they choose to have". We might say the one they can, they must, and are bound to have. The "role you make yours" is obviously a convenient expression, frequently used by medical staff, even if somehow vague and ambiguous. The absence of boundary lines are another cause of caregivers' suffering [6].

It is not very likely to be an option in the event of contention when it concerns a medical act, but it clearly expresses a pragmatic principle. Actually, for the relatives, the disease is not only seen as a new obligation but as an unavoidable duty to fulfill, with loneliness as a companion [7,8]. We point out here a source of stress for main carer and an origin of his possible burnout: a gap can exist between the compulsory daily chore and technical practice, and sometimes the moral rules carers are supposed to follow: "Support is forbidden". We thus become aware that the boundary lines are not really clear to define between what you are obliged to do, and where you are free to choose. The concept of a "hidden side of the help" is often met in medical literature about caregiving, and certain add an "invisible carer", "invisible victims".

Caregiving implies reflection and not a superficial approach, as if care could be considered as a "namby-

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pamby attitude". Moreover, families and health professionals demand an ethical and political position concerning care given to the others as a real answer to their needs. Informal caregiving and professionals' commitment are a kind of team for the sick and their families. This concept seems clearly missing in the psychological representations of the blind technocrats, as if caregiving did not have a negative impact on health, employment, income and family finances [9-11].

Owing to this invisible side to the reality of caregiving we may genuinely fear that the most vulnerable people could become more and more excluded. Conversely, General Practitioners and nurses working with the elderly living in home dwellings have a special view of the carer, sometimes at a loss and exhausted, depressed [12,13] or already beyond the point of no return. Brandishing the sense of duty, handing him over to justice or leading him hypocritically to commit euthanasia cannot be the human solution [14]. Caregiving cannot exist but in the development of a health policy of solidarity. Now, the question is: Are the decision-makers responding to this new way of thinking of care, to this new social and political challenge the epidemic of chronic diseases represents?

2. THE ROLE OF THE FAMILY CARER IN FACILITATION OF ACCESS TO CARE BY THE HELP RECEIVER

Very often, families are unable to cope with the demented patients' situation, and ask for help. Over and above the basic burden, with time availability shrinking, and the costs, direct or indirect, having to be monitored, the addition of court proceedings and politicians intervening, the family and the old patient are placed under enormous emotional stress at an already difficult time by making public what should essentially have been a private matter. In any country, the legislature has a particular ethical and moral responsibility, to the growing elderly population, to preserve their right to self-determination before that right is forever lost in the morass of bureaucracy.

As an instance of this, in the "Guide of the Family Carer" written in 2007 by the French Government Department of Employment, its authors refer to the role of the informal caregiver, for instance when he makes an appointment with the doctor and takes the sick person along for the visit, the guide has this to say: "You make the access to medical care easy and organize the appointments with the health professionals. Are you the one who makes the appointments? Are you there when the nurse (or any other professional) comes to your home? Do you take him/her to the doctor's?"

When dependency and handicap occur, the carer is often the commander who fights for access to care for his

relative. Demented persons are not always welcome in Emergency Departments. The carer worries about the latter's withdrawn attitude and is afraid of being stigmatized. He also feels concerned about the risk of forgetting patients or leaving them in neglect when they go out of the care units system, subservient to medical treatment pricing.

The Law, as it is written, supposes a guarantee of equal access for each person to any care his health condition may require, as well as the continuity of the medical care and the best health security possible to each one. But development of the system of access to medical care must be thought of within an overall reflection about health and social welfare. The carer's integration is still here in its early stages even if we can observe the difficulty or even the lack of access to care, for lack of first aid options or of a decent medical demography.

As a result, weaknesses in the organization of the so-called health system can be noticed: Thus, in spite of the successive reforms of the last twenty years (hospital reforms or rescue plans of the health insurance), we can see that at the dawn of the twenty-first century some ill people end up out of the health system while some others must face unacceptable waiting periods and some more, particularly vulnerable ones (elderly or handicapped people) are not taken into care in suitable places. We could even add the elderly patients more and more numerous who are sent to units cynically brought into discredit and described as "exit units". The fact that we don't take care of these people or do so quite late affects people's fundamental rights, namely the right to health welfare, the fact that everyone is entitled to their dignity, the principle of non discrimination. It also has an economic and social impact linked to the aggravations of new pathologies, to the sick leaves, which obviously leads to an increase in the expenses of the social welfare, emergency cases and premature deaths [15]. This is particularly striking concerning the handicapped: the lack of availability of their carers to the access to medical care represents an aggravating element for their own health condition [4]. The time required is in fact mainly taken from their professional or family life, which plays a great part in their exhaustion or burnout risk [15]. Furthermore, the burden is not much buffered, for lack of a large family or temporary accommodation. That's while difficulties appear concerning the access to medical care for people with a handicap. Thus Hinglais, speaking about the reception at the emergency department, points out: "Someone with a handicap is treated the same way as all other. Now, it is prejudicial to make someone with psychic disorders, someone who is quadriplegic, someone with after-effects of a head injury..., and his nearest family carer wait for many hours in the emergency department or even in a hospital waiting room for a consulta-

tion”!

3. THE FAMILY CARER, BETWEEN DIGNITY AND CARE

We must here encourage and support the role of the informal carers in order to strengthen the link between dignity and care [16]. Patients' dignity is based on access to medical care, the core of the medical treatment and the most essential right of ill people. As far as the nursing staff is concerned, to deal with the access to medical care is not only a way to respect the right to this access, but is also a way to make it more effective by building up cooperation with the family carer. All this aims at making the sick person feel secure/reassured and at making what should be, refer to a subjective right exist. Apart from the fact that we are speaking here about a task of outstanding importance, this would give the family carer his own task consisting in promoting the medical treatment, at least with its carrying out.

Access to health care is too often discussed in purely economic terms, but those concerned with ethics should also consider cultural and familial barriers to receiving medical services. It concerns the old patient, but also the caregivers. How to have a surgery, a several day hospitalization, when you are alone to care for a demented patient at every moment? Then the following care and the support would have to be set up. We would have to improve this concept, namely access to medical care, concerning the curative, preventive and terminal care, these are the significant features of caregiving. Some alarming reports refer to the administrative deafness concerning numerous patients (about 20%) who would give up treatment like their caregivers, trapped in a help system which is not “bounded”, harmonized or supervised [4,16,17]. To take care of a sick person at home has quite clear consequences on the health of the one, who, from within the family, takes care of him/her. Twenty per cent of carers say they delay, and even give up going to the surgery or to hospital or getting medical care for themselves.

How many of them really do this because they lack time, how many of them also do it because they have not found any reactions in their own family, or with health professionals? For many, especially for a husband or a wife, no longer to have the opportunity, to delay treatments means no longer to have the opportunity to take care of his/her own health. Will the announced setting up of the future respite care and support programs for the family caregivers change this situation? Can we, must we actually forget that an excessive high death rate among the carers (a husband or a wife) (in the case of Alzheimer's disease for instance), a frequency of nervous breakdowns two times more common or even a risk of ill-treatment may exist?

This cruel banality of the burnout of the “carers” makes each professional think about the risk of an ethical drift clearly occurring when the help does not consider the caregivers or the one who needs care as unique but just as a “person with cancer”, an “Alzheimer patient”, a “carer” disappearing under the cloak of anonymity of the group. Because as Coraz notices: “indifference leaves the door wide open to the inability to think which is so clearly denounced by Hannah Arendt through the concept of banality of evil: “the worst was done by the normal men, “standard” people whose only abnormality was their indifference, their inability to think”. The fact that a “dignity gap” has become commonplace among these “loving ones” helping/taking care daily of a sick person quite often left out or whose deep suffering is neglected, nowadays appears in the mind of some zealous decision-makers only in terms of health savings, control of spending which makes them get promotion. We actually take a great risk of seeing the carers loose sight of their own needs regarded as unimportant compared with those of the patient [18]. Instead of health savings we could rather speak about delayed medical treatments which are certainly more expensive than if they were done in time.

If to take care does not go without saying but falls within the competence of a duly acknowledged professional activity and is thus protected as such, when dealing with the transfer of the tasks, if they do exist in some precise situations such as dialysis, we can say it must remain very much supervised and kept for skilled paramedics. Thinking of that and in order to prevent the family caregivers' burnout, it is necessary to think about the transfer of the medical “skills” to the professional caregivers and to organize a system of dependency insurances. The best way to help the caregiver is to promote homecare, to fund the dependency consequences. Draft legislation introducing “dependency insurance” was approved by the Chamber of Deputies on 27 May 1998 in Luxembourg, and was introduced in 1999 in the United States, covered solely by the employee at a contribution rate of 1.40% of salary. Sustain the oldest of the old, the demented patients, the family caregivers. “Le serpent de mer” or “sea-snake” is a commonly used expression in French, “an old chestnut”, “an issue that will not go away”, but, in many western countries, an idea bandied about during all national election campaigns... up to the actual polling, of course.

And “If , so far, the family carers have not had the opportunity to get access to the skills, apart from those concerning nursing care, pointing out that the home nurse must train the carer (...) how many of these training schemes, planned to reduce the shortage of the professionals, are really brought into play?” asks a patient's caregiver. Moreover, beyond this quantitative side, what can taking care still mean when it implies you must deny

yourself?

4. CONCLUSION

Carers who are too committed, too lonely, confronted with medical treatment and at a loss when having to handle medical care without having assimilated and understood well what has to be done because things have not been explained or hardly, cannot but become potentially dangerous. The medical follow-up remains at present quite selective in most cases with a possible reorientation towards a doctor (a family doctor and/or a specialist), and also towards family associations at the same time, too rarely towards a psychologist. This is however, fundamental in order to fight against the carers' loneliness, nervous breakdowns, possible aggressiveness... If we do not adapt the help we describe as informal/natural, (thus called to forget whether the government does make any sufficient effort to make it official), can we seriously expect to limit the potential "abuses" described by the medicopsychological clinic of the ageing carer's burnout? Self-regulation refers here to fantasy—which can lead to exhaustion—even if we have in mind that supportive intervention towards caregivers of patients with Alzheimer's disease could allow patients to remain at home longer [1]. Although the carer has definitely got a vital place, isn't it important to clearly express the limits to the carer's involvement right from the beginning of the training time, in order to safeguard the recognition of this vital place? At the moment, in spite of their goodwill, the Rating Notation by International Agencies of the Health Systems cannot give a triple-A to many Western Countries for the protection of the carers of chronic or demented patients.

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