

# ETHICAL IMPLICATIONS OF THE INSTITUTIONALISING PATIENTS WITH DEMENTIA

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## **Abstract**

*The psychological stress of the families with patients suffering from dementia seems to be much more complex than the one caused by the mere responsibility of caring for a patient with disabilities. The challenge of the caretaker is psychological, physical, financial and social. The persons looking after the patients with dementia can take better care of these patients if, in their turn, they take better care of themselves both physically and psychologically. A great part of the patients with dementia will require, at a certain moment in the evolution of the disease, hospitalization in a nursing home or in other institutions specialised in assisting such patients. A particular care in what the assisting of institutionalised patients is concerned is the use of physical constraints and antipsychotic medication. The significant role of the psychiatrist in these services resides in educating other doctors and medical personnel. The families and the patients may manifest a feeling of loss and at the same time to perceive the stigma associated with this affection. The institutional assistance takes care of the patient in the last phases of his/her disease, a period of time in which the relatives face great difficulties, has a great importance and it has the advantage of assuring a quality medical care, preserving the dignity and, as far as possible, the autonomy of persons with dementia. The decision to hospitalise a relative in a special institution is difficult and it must be reached by the relatives together with a multidisciplinary team, but it can also be the consequence of a period of crisis.*

**Key words:** *psychological stress, physical constraints, antipsychotic medication, stigma, multidisciplinary team, autonomy, dignity, costs, institutional assistance, compromise.*

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The psychological stress of the families with patients suffering from dementia seems to be much more complex than the one caused by the mere responsibility of caring for a patient with disabilities. It has been estimated that approximately 30% of the partners caring for patients with dementia will develop depressive disorder. The prevalence of depressive disorders in the case of the adult sons of patients with dementia and who look after them varies from 22%, in the case of those without a history of affective disorder, up to 37% in the case of those with a history of depression. (7)

The caretakers present a high risk for somatic affections, depression, weight loss, insomnia, alcohol abuse, increase of psychotropic medication intake due to the increased stress level, with the possibility of experiencing feelings of guilt, shame, wrath, helplessness, rage and disappointment along with verbal or physical abuse of patients with dementia. The health of the persons looking after the patient with dementia is frequently neglected although it is essential. The doctor must insist on an appropriate nutrition, sufficient sleep and moderate ingestion of alcohol and caffeine. (1)

The challenge of the caretaker is psychological, physical, financial and social. We can reduce the burden falling on the caretaker with some help for the family from the part of the community, acquiring some knowledge, creating harmonious relations within the family, providing counseling and emotional support. The persons looking after the patients with dementia can take better care of these patients if, in their turn, they take better care of themselves both physically and psychologically. The way in which the caretaker communicates in his attempt to change certain behaviour may determine the success of that attempt. (7, 8)

Due to behavioural problems, of associated affections and the loss of social support, a great part of the patients with dementia will require, at a certain moment in the evolution of the disease, hospitalization in a nursing home or in other institutions specialised in assisting such patients. Approximately 2/3 of the residents in nursing homes suffer from dementia and 90% of them present behavioural disorders. The personnel working in these institutions must possess knowledge on the management of non-cognitive symptoms. (5)

Adequate stimulation, autonomy increase as well as adapting and changing capacity, along with the progression of the disease, is very important in these institutions. A particular care in what the assisting of institutionalised patients is concerned is the use of physical constraints and antipsychotic medication. The long term use of antipsychotic medication requires a periodical evaluation of the response to medication, the monitoring of side effects and an adequate documentation. Risk factors for late dyskinesia are advanced age, feminine sex and cerebral traumatism. (8)

Due to unrest and aggressiveness, methods involving physical contention are sometimes used in these centres. However, the resort to such methods occurs as rarely as possible and there are even suggestions that contention methods contribute to the accentuating of cognitive decline. The reduction to a minimum of the use of constrictive methods is possible through changes of the surroundings in order to reduce the risk of wandering and through careful evaluation and appropriate treatment of the probable causes for the unrest. (9)

Patients with dementia find it hard, if not impossible, to communicate the location or presence of pain, hunger and

other unpleasant conditions, a careful evaluation of nervousness or of any irritability condition being necessary in order to identify such a situation. The significant role of the psychiatrist in these services resides in educating other doctors and medical personnel. The patients and their families face the admission of the existence of the disease and of the limits it implies.

The families and the patients may manifest a feeling of loss and at the same time to perceive the stigma associated with this affection. It can be useful to identify the lost abilities and to put in value the remaining abilities. The less affected patients must be advised to give up driving. The patient must name a representative in order to make decisions about the financial and medical future and he/she must draw up his/her will.

The family must be advised to consider taking over financial problems and patients must be forbidden from driving vehicles. The family must consider hiring a helping person at home or a possible transfer to a special caring institution, during the middle stage of the disease, due to the increase in patient's dependence. (1)

Hallucinations and delirious ideas may frequently appear, and these could frighten the family. It is advisable to inform the patient and the family that such symptoms come across often in the developments of the diseases and they are treatable in most cases. If the psychotic symptomatology is associated with a behaviour which endangers the life of the patient and of the ones around, it must be treated pharmacologically through administration of small doses of antipsychotic medication.

In advanced stages of the disease, patients are severely incapable and almost completely dependent on the ones around for simple functions, such as

feeding, dressing, and personal hygiene. Families face mixed feelings of guilt, excessive burden and loss. (2)

The doctor must warn the family to prepare for the patient's death. In an ideal situation, all the discussions about tube feeding, infections treatment, cardiopulmonary resuscitation and intubation must have taken place when the patient could have actively participated in reaching a decision, but, in any case, it is important that such a discussion should take place before one of these options becomes urgent. Institutionalising is frequently necessary in the last stage of the disease, generally the patient's hospitalization in a caring medical institution providing physical assistance (focusing mainly on nursing rather than on medical intervention) and emotional support for the family during the patient's last months of life.

The most frequent causes for non-compliance are connected to the feeling of the uselessness of treatment due to the progressive degrading evolution of the disease, of the daily obligation of medicine administration, of the family's level of education, of beliefs, cultural patterns and the eventual side effects of treatment. (3, 4)

The fact that the institutional assistance takes care of the patient in the last phases of his disease, a period of time in which the relatives face great difficulties, has a great importance. Institutional care for the patient him/herself means most of the times a loss of autonomy and most frequently a loss of individuality. Institutional assistance has the advantage of assuring a quality medical care. Institutionalising has to ensure the preserving of dignity and, as far as possible, the autonomy of persons with dementia, replacing the role of the family and of the caretaker. (6)

The decision to hospitalise a relative

in a special institution is difficult, being accompanied by feelings of guilt, but it has also positive aspects such as the improvement of sleep and family mood. The decision about “when” and “if” should he/she be admitted in a “nursing house” must be reached by the relatives together with a multidisciplinary team, but it can also be the consequence of a period of crisis, with the multiplication of the problems at home. (5)

Armstrong noted in a small study that a many patients are placed in institutions around Christmas and, of course, the holiday period is particularly tensed. The changing of the ambient, the visiting relatives from far away and generally the stress and anxiety of such periods can add some extra tension on the one taking care of the elder. It has been noted that in England there is a preference for private institutions compared to public ones. This indicates the importance of costs and allotted funds, besides the importance of the moment in which the admission takes place. (1, 9, 10)

Hope states that the factors which determine hospitalization for a medium period of time are different from the ones which hasten institutionalising for large periods of time, the last ones being represented by behavioural disorders,

particularly aggressiveness. Patient features that predict entry to long term care include severity of functional impairment and behavioural disturbance as well as incontinence and physical immobility. A series of longitudinal systematic studies have shown that a part of the patients with severe affections are admitted in nursing houses – this being a functional solution but not the best. Except for the caring factors and treatment, the availability of other resources also delays long term hospitalisation. A few studies also show the growth of care for services along with the growth of hospitalising risks in nursing houses. (10, 11)

### Conclusion

The choice of a caring unit inevitably represents a compromise. On the one hand there are the patient’s needs of having a climate as familiar as possible, and on the other hand the conditions must be safe and “transparent”. It is actually a compromise between the life regime desired by the patient (with the family, peer or alone) and the conditions assured for his/her support (in groups). It is, as usually, a compromise between what we want and what we are offered.

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