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pour l' évaluation et le suivi des personnes âgées fragiles  
ou démentes**

Georgina Corte Franco

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Georgina Corte Franco. Actimétrie de l'environnement. Un nouveau concept pour l' évaluation et le suivi des personnes âgées fragiles ou démentes. Sciences de l'Homme et Société. Université Joseph-Fourier - Grenoble I, 2010. Français. NNT: . tel-00538556

**HAL Id: tel-00538556**

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**Université Grenoble**  
Ecole Doctorale ISCE

Ingénierie pour la Santé, la Cognition et l'Environnement

---

**THESE**

Pour obtenir le grade de Docteur de l'Université de Grenoble

Spécialité de thèse: Mouvement et comportement pour la santé et l'autonomie

**ACTIMETRIE DE L'ENVIRONNEMENT. UN NOUVEAU CONCEPT  
POUR L'EVALUATION ET LE SUIVI DES PERSONNES AGEES  
FRAGILES OU DEMENTES**

**ENVIRONMENTAL ACTIGRAPHY. A NEW CONCEPT TO EVALUATE AND FOLLOW UP  
FRAIL ELDERLY OR PERSONS WITH DEMENTIA**

Thèse présentée et soutenue publiquement par

Georgina CORTE FRANCO

Le 18 juin 2010

**Directeur de thèse**

Pascal COUTURIER, Professeur, Université de Grenoble

**Membres du Jury**

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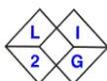
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LABORATOIRE INTERDISCIPLINAIRE DE GERIATRIE ET GERONTOLOGIE-CHU GRENOBLE



## Aknowledgements

This work could not have been done without the funding from the Mexican scholarship I got from the

CONSEJO NACIONAL DE CIENCIAS Y TECNOLOGIAS (CONACYT)

Registration Number 177072 starting in November 2006 and finishing at the end of October 2009.

I personally appreciate that a country like mine offers such an opportunity and I hope that the work done will help to the development of gerontechnology in Mexico. Being alone with two small children in a foreign country without this funding it would have been impossible for me to achieve this work.

I do also want to thank the participation of GRECO foundation. Thanks to the funding in the project I could present the work done in different scientific meetings.

Finally the acceptance to join the European project MIDAS (Multimodal Interfaces for Ageing and Disabled Societies) will allow me to continue on this research field as a post doctorate. I will try to develop my knowledge hoping that I will be able to help elderly people get a better quality of life.

*A Sandrine y Géraldine, por comprender a su temprana edad el significado del tiempo dedicado a una larga tarea, pero que al final vale la pena la espera. Si, al fin ya terminé mi tesis.*

*À Sandrine et Géraldine, pour avoir compris à leur âge la signification du temps dédiée à une tâche si longue et combien ça vaut la peine: Oui: enfin j'ai fini ma thèse.*

*Gracias a ti «Yoya», mi mamá, por apoyarme siempre desde México.*

*Merci à toi, Yoya, ma mère pour tes encouragements depuis le Mexique.*

*Agradezco enormemente a mis amigos aquí en Francia por su apoyo y tiempo durante estos años y que me permitieron terminar este proyecto.*

*Un énorme merci à tous mes amis en France pour leur soutien et temps pendant ces années qui m'ont permis de finir ce projet. Merci à: Brigitte, Christiane et Cathy.*

*Especialmente quiero agradecer a mi director de tesis, Pascal Couturier por su comprensión, sus comentarios, su apoyo pero sobretodo por haber confiado en mí.*

*Spécialement je remercie mon directeur de thèse Pascal Couturier pour sa compréhension, ses commentaires, son soutien, mais surtout pour sa confiance.*

*Este trabajo no hubiese sido fructífero sin la ayuda del Dr. Soutrik Banerjee, su ejemplo y trayectoria inspiraron una gran parte de este manuscrito y sobretodo agradezco su valiosa ayuda como estadístico.*

*Ce travail ne serait pas si productif sans l'aide du Docteur Soutrik Banerjee, son exemple et ses travaux ont inspiré une grande partie de ce manuscrit. Je le remercie surtout pour son aide comme statisticien.*

*Quiero también agradecer a todos los miembros de mi jurado por haber aceptado revisar este trabajo y por sus valiosos comentarios.*

*Je voudrais aussi remercier les membres de mon jury pour avoir accepté de réviser ce travail et pour leurs précieux commentaires.*

### Notes from the author

The following manuscript is a compilation of different projects where I did have the opportunity to participate during the years of my doctorate.

As a Mexican geriatrician and being sponsored by my country I always kept in mind that the type of research and specially the outcomes of this research had to be applicable in Mexico too. The main field of my work "gerontechnology" is a rather new discipline in geriatrics that will gain more importance in our "high-tech" society. For me as a clinician being involved in the development of new technologies was completely new. At the beginning personally I was not so convinced about its applicability and four years later I am devoted to it.

In geriatrics, clinicians are used to treat patients according to guidelines and following some medical classifications and sometimes influenced from pharmaceuticals. We even have geriatric syndromes. Now, with the intervention of technology in the field of geriatrics and gerontology, the way of seeing an older person has changed. Technology for the elderly can offer us a new option to evaluate, follow up, survey and help with therapeutically interventions of older persons. The best point is that innovative technology can now be adapted to the living environment of the person, at home or in an institution and even in a hospital. New generation of technologies are always in arrival (Doughty, 1996).

## RÉSUMÉ DE THÈSE

Le vieillissement est un enjeu pour la société et notamment en termes de santé publique dans les pays industrialisés. La prise en charge ne peut se limiter à un personnel jugé insuffisant pour s'occuper des personnes âgées qui vieillissent à domicile et les nouvelles technologies offrent des solutions complémentaires possibles. L'objectif principal de ces expérimentations était de démontrer l'utilité de l'actimétrie environnementale comme outil d'évaluation et de suivi de l'autonomie chez les personnes âgées à domicile et en milieu hospitalier ayant différents degrés d'activité physique et cognitive. D'autres paramètres comme l'activité nocturne ont été spécifiquement étudiés pour évaluer la performance et les troubles du comportement des patients déments.

Le premier chapitre est un état de l'art sur les principaux thèmes tels que la démographie concernant le deux pays ou les connaissances acquises seront exploitées, la France et le Mexique. Puis la description des variables qui sont importantes comme l'autonomie et sa relation avec la démence, les troubles du comportement nocturnes, la dépression et son évaluation par l'actimétrie sont présentés. Ensuite, le deuxième chapitre est une réflexion éthique sur certaines technologies innovatrices dans l'évaluation de la performance des personnes âgées. Une analyse sur les contraintes existantes pour développer les nouvelles technologies et les mécanismes impliqués dans ce processus sont proposés suivis des résultats d'une enquête faite auprès d'un groupe concerné dans le développement des technologies et un groupe participant à un espace éthique. Le troisième chapitre concerne l'expérimentation d'un système qui détecte le niveau d'autonomie des personnes seules à domicile par l'analyse des signaux électriques venant des appareils électroménagers. Ce système permet d'envisager de futures applications, car il détecte la probabilité d'avoir réalisé une activité de la vie quotidienne et mesure donc le niveau d'autonomie. Ce système révèle des anomalies dans les habitudes de la personne, comme une diminution de son activité globale et génère une alarme pour alerter son entourage ou des professionnels du soin tel que le médecin traitant. Le chapitre quatre explique les résultats de l'utilisation de l'actimétrie par capteurs infrarouges dans un usage hospitalier. Ce système permet d'avoir un registre de l'activité au lit, dans la chambre et dans le toilette en continu, et peut faire la différence entre l'activité du malade et celle d'autres personnes dans la chambre. Ce travail est ciblé sur l'activité nocturne, paramètre de référence pour évaluer les différences d'activités en présence des troubles cognitifs, dépression ou différents niveaux d'autonomie. Les résultats montrent l'importance de la présence des symptômes dépressifs sur l'activité nocturne chez les sujets contrôles et l'effet paradoxal chez les déments, qui voient cette symptomatologie diminuer leur taux d'activité nocturne. Connaître le taux d'activité nocturne peut aussi être utile pour suivre les effets des thérapeutiques, comme cela est présenté dans le chapitre cinq qui analyse en détail le cas d'un patient dément suivi pendant 79 nuits. Dans la chambre actimétrique. Ce nouveau paramètre peut servir à mieux connaître le fonctionnement des patients qui ont un syndrome démentiel et plus spécifiquement les troubles du comportement nocturne. Enfin, parce que le personnel soignant est moins nombreux la nuit et qu'ils ont tendance à s'habituer aux comportements aberrants des malades, ils oublient de notifier les modifications d'activité sur le dossier de soins. Le chapitre six concerne ainsi la validation d'une échelle semi qualitative d'évaluation du comportement nocturne utilisant l'actimétrie comme gold standard. Cette échelle simple et facile à utiliser par le personnel soignant permet d'améliorer le recueil du comportement nocturne dans le dossier médical. Finalement le chapitre sept ouvre une discussion qui résume l'ensemble des travaux présentés pour démontrer la réalité du concept d'actimétrie environnementale et ses applications actuelles et futures.

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## INTRODUCTION

Un des enjeux principaux pour un gériatre est de faire une bonne évaluation du patient en tant que malade, membre d'une famille et de la société. Pour réussir une évaluation adéquate on se sert des échelles cliniques qui prennent en compte la fonctionnalité, ses performances dans la société et dans la famille en gardant comme objectif principal d'aider les personnes âgées à rester le plus longtemps autonomes et en sécurité à domicile. Ceci est la raison principale pour laquelle il faut identifier les personnes fragiles. La fragilité est un syndrome gériatrique assez complexe qui comprend de nombreuses composantes telles que la performance physique et cognitive, les comorbidités, d'où le besoin d'évaluer ces variables. Les nouvelles technologies peuvent être une aide à cette évaluation. Par contre, le développement rapide de ces nouvelles technologies doit être encadré sur le plan éthique et juridique. Nous proposons d'abord une classification des usagers selon leur profil d'autonomie. Selon ce profil, différentes technologies peuvent être envisagées. L'autonomie peut être évaluée par l'actimétrie environnementale dont deux variantes sont présentées. L'une est la mesure des signaux électriques provenant des appareils électroménagers, qui donnent une probabilité d'avoir effectué une activité de la vie courante, pour les personnes seules à domicile. Et l'autre variante utilise des capteurs infra-rouges pour évaluer le taux d'activité chez les patients hospitalisés. La fiabilité de l'actimétrie par capteurs infra rouges a été démontrée. Les capteurs sont localisés de façon stratégique pour permettre la détection des mouvements dans la chambre, les toilettes et l'entrée. Un rapport automatisé donne le taux d'activité selon le type de déplacements et l'activité au lit. Ce rapport est surtout utilisé pour quantifier l'activité nocturne, un paramètre utile dans l'évaluation des troubles du comportement notamment chez le sujet dément. A la différence de l'actimétrie embarquée, les capteurs sur l'environnement sont discrets et ne dérangent pas le patient. Les applications de l'actimétrie environnementale peuvent être variées en milieu hospitalier: soit pour identifier le taux d'activité chez les patients déments avec troubles du comportement surtout nocturnes, soit pour le suivi d'une thérapeutique. Mais aussi en tant que «gold standard» pour valider une échelle semi quantitative qui évalue le comportement nocturne.

Toutes les technologies au service des patients et des personnes âgées à domicile doivent faire partie d'une évaluation éthique à côté de leur validation ergonomique et clinique. Plusieurs cas sont analysés et l'opinion des chercheurs, des éthiciens et des usagers est indispensable. L'usage des technologies innovatrices a toujours fait partie du milieu médical et a contribué à son développement.

## INTRODUCTION

Probably the most important challenge for a geriatrician is to do a good evaluation of the person as a patient, as a family member and about his role in the society. This is what really differentiates this discipline from other medical specialties. The proof is that most of the clinical scales that we use to evaluate an older person involve their functionality, their role and performance in society and we even dare to ask their family members or caregivers about the reliability of the information.

Some pure medical scales and laboratory parameters used for younger adults can be applicable to elderly patients and others have just been modified or adapted according to the ageing process. The same has been done for most of the drugs used in geriatric patients.

We have as a major goal to try to help elderly stay as autonomous as possible. But we also know that sometimes when the patients come to their physician's office it is mainly because they are sick or have a problem in a stage that can hardly be helped. For this reason in geriatrics we have a standard geriatric evaluation that takes into account all spheres of the geriatric patient and so called geriatric syndromes have been recognized. Therefore we decided to get involved with a new way to evaluate patients that might be frail. Frailty in general has been defined as a state of vulnerability; it can mean easy to break, to get sick, to die. Since older people are more exposed to co-morbidity, this parameter has been largely studied and experts have been involved to better define and find main risk factors (Walston, 2006). It will be commented later. The typical image of an older person, who looks thin, with a diminished muscle mass, curved, who has difficulty to walk or walks and moves slowly and who also has sight and hearing problems could be the prototype of frailty from a general point of view. But this image can evidence some of the main parameters that are evaluated with most frailty indexes. Frailty increases with aging and gender can influence it depending on the population studied, for example women can be more affected according to (Song, 2010) but men are more involved when the patients studied have cognitive problems (Pjipeers, 2009).

But there are also other ways to evaluate this state. It is comprehensible to admit that cognitive impairment is a risk factor for autonomy loss and frailty, but physical frailty might be also a risk for cognitive problems (Boyle, 2010). Therefore when dementia appears and it worsens, behavioral problems appear and this becomes a great burden for the patient and the caregiver, being a major risk factor for hospitalization in psychiatric wards (Hermann, 2008).

These behavioral problems related to dementia (BPSD) are so important and are mostly accompanied by a sleep alterations and nocturnal hyperactivity. There are also authors that created

frailty scores for this population with psycho-geriatric problems, having always mortality as main outcome (Pipers, 2009). Higher ratings of behavioral problems in the person with dementia are also significantly associated with transition into residential settings, taking into account the psychological domain of quality of life of the caregiver (Banerjee Su, 2003). Therefore one of the main reasons why we decided to evaluate nocturnal behavior through activity is to avoid caregiver's burnout and to better follow up problematic patients. There are several studies that have shown that actigraphy can be a reliable way to measure activity in patients with dementia (Ancoli, 2003). Nevertheless most of the studies are done with wearable sensors and this can sometimes bother patients mainly if they are agitated. An important factor to justify its use is that even in developed countries like France, there is not enough health personnel to better evaluate nocturnal behavior and therefore information on this issue is sometimes missing or inaccurate.

Environmental actigraphy can be a good solution, it is non intrusive and is better suited for units where during the night less personnel is available. It gives reliable data about the level of activity that a person can have and it can be used for the follow up of patients with nocturnal hyperactivity (Banerjee, 2003).

Technologies that involve the environment can be a new option to quantify activity and indirectly the level of autonomy. This means that a smart home or a smart environment can combine different types of sensors that will interact to deliver reliable information about the person's performance for example measuring electric signals coming from electro domestic appliances (Corte, 2007). It has been suggested that the environment can help diagnose dementia, when the level or the typical pattern for an individual begins to change (Suzuki, 2005). But this point brings us to a new issue, the ethical constraints that are implied in the use of these innovative technologies (Rialle, 2008).

Are we really aloud to survey a person in his personal environment? How far can we or should we go? Who is going to regulate this technological boom?

Along this manuscript, most of these points will be covered.

Chapter 1 is an overview of the demographic phenomena more related to these objectives of the whole work done, then at the end there is a description of the main aspects and the global objectives of all the experiments done during these years. Therefore the second part called "results" is conformed of different chapters. Most of the chapters represent an experiment and some of them correspond to a publication. Chapter 2 is the sum of some reflexions about the main ethical issues that can appear while developing and using innovative technology in the field of gerontology, adapted to the type of technologies used in a project. Chapter 3 is a study done in collaboration with France Telecom Research and Development, where we did evaluate the usefulness of

environmental sensors at home to verify the level of activity and autonomy from older persons living alone. Chapter 4 is focused on the use of nocturnal actigraphy with hospitalized patients, analysing as outcome variables: cognitive status, depression and autonomy. Chapter 5 is a case report from a patient that was observed over a longer period of time and that exemplifies well the applicability of actigraphy in daily work in a geriatric ward. Chapter 6 is about the validation of a semi qualitative scale to better score nocturnal activity by medical staff using nocturnal actigraphy as the gold standard.

So each chapter has again its own objectives and methodology, results and discussion if appropriate.

The last one, chapter 7, is a general discussion about all chapters and ends up with a general conclusion.

So, this manuscript is concise and tries to present in a comprehensible way the different perspectives of the use of environmental actigraphy.

## **RESUME DU CHAPITRE 1**

### *ETAT DE L'ART; ASPECTS IMPORTANTS DE LA DEMOGRAPHIE, DE L'AUTONOMIE DES PERSONNES AGEES, DE L'ACTIVITE, DE LA DEMENCE ET DE L'ACTIVITE NOCTURNE*

Ce chapitre donne une idée sur les principales données démographiques concernant le vieillissement dans les deux pays où les résultats seront utilisés, le Mexique et la France. Nous tenons compte principalement des données liées à l'autonomie ou au handicap. Nous proposons ainsi une classification de la population âgée en groupes selon leur niveau d'autonomie ou de handicap et leurs besoins, afin de mieux cibler les aides technologiques.

La fragilité, liée à la perte d'autonomie et sa relation avec des troubles cognitifs et la démence est exposée. L'évaluation de l'autonomie a toujours fait partie de l'évaluation gériatrique et elle est primordiale chez les sujets ayant des troubles cognitifs. C'est la raison pour laquelle nous avons un intérêt particulier pour les troubles du comportement nocturnes en tant que facteurs de risque de l'épuisement de l'aidant et l'institutionnalisation du malade. Compte tenu que les troubles du comportement nocturnes sont les plus difficiles à évaluer, nous présentons l'actimétrie comme une solution fiable et acceptable. Actuellement on compte sur des guides assez précis pour l'usage de l'actimétrie embarquée, une méthode validée principalement pour les troubles du sommeil. Par contre pour l'actimétrie environnementale les recommandations ou guides sont inexistantes, bien que certaines définitions puissent être appliquées. Ainsi l'actimétrie environnementale est proposée comme une méthode fiable, non intrusive et qui ouvre de nouvelles perspectives dans l'évaluation de l'autonomie à domicile et de l'activité nocturne en milieu hospitalier. Cet état de l'art donne les bases utiles à la compréhension des chapitres suivants qui traitent spécifiquement des travaux menés dans les différents domaines de l'actimétrie environnementale.

## STATE OF THE ART

### CHAPTER 1 IMPORTANT ASPECTS ABOUT DEMOGRAPHICS, ELDERLY, AUTONOMY, NOCTURNAL ACTIVITY AND DEMENTIA

#### 1.1. Demographics about ageing

World population ageing has become a threat to the health budget and a social problem. Life expectancy has increased steadily and considerably in the European countries. This reflects a consistent reduction in mortality rates at all ages, due to such factors as higher living standards and educational levels, healthier lifestyles and improved access to and quality of health services. France with an elderly population ranging in the first places according to the reports from the World Health Organisation (WHO) and regarding life expectancy, a person between 75 and 79 years old might live 12.8 years (European Health Report, 2009).

But this phenomenon is not spared to well develop countries; special attention should be given to countries with an economic and social transition with a fast elderly group increasing. The main countries in this group according to the world health report are: Brazil, Venezuela, Mexico, Thailand, India, China between the ten first ranked.

The definition of an "old person" is not universal since each country faces the problem of a fast growing ageing population in a different way. According to the WHO definitions this issue fell into three main categories: 1) chronology 2) change in social role (*i.e.* change in work patterns, adult status of children and menopause) and 3) change in capabilities (*i.e.* invalid status, senility and change in physical characteristics) (Glascock, 1981). Results from this cultural analysis of old age suggested that change in social role is the predominant means of defining old age. When the preferred definition was chronological, it was most often accompanied by an additional definition. So for Mexican standards the age of 65 is still a good age limit to define an elderly person. In France due to their high longevity, for clinical purposes geriatric patients are considered at age 75. Nevertheless the 65 years age limit is still applicable for other purposes.

Another and more realistic factor for health epidemiology is the Disability Free Life Expectancy (DFLE) a more realistic marker and with impact on the environment (Robine, 1989). This variable is directly related to quality of life factors and is also probably the major goal in geriatrics Disability is a generic term defined as *the impact of disease or injury on the functioning of individuals* (Mathers,

2000). It covers various situations from the rather common functional limitations to restrictions in daily activities and finally dependency.

Each country faces this phenomenon differently and it is a major issue in politics, not only because of the costs of all future retiring persons, but mainly because the older population are great consumers of health services and budget, with a high hospitalization and institutionalization rates. In countries like Mexico, this implies great costs not only for the national health budget, but also for the families, because around one third of the older population are not covered by the social security. For example cost related to falls and other accidents have been also recognized as a burden for the health system (Ruelas-Gonzales, 2008). In general, family has been a main support to the care of elderly in different ways, either by sustaining their elderly at home or by supporting them financially. But what happens if family do only have one child?

It is fine to have a population ageing phenomenon but two main issues are immediately questioned:

- 1) We live longer but do we live better? With fewer handicaps? Is successful ageing really happening?
- 2) Who will pay and take care of the new growing population ageing?

For instance, we can consider the results from a population study done in Thailand. This country has a comparable economic and social development as Mexico according to WHO standards.

In a national population survey they studied 4048 subject over 65 years. Jitapunkul found a prevalence of 19% (95%CI 17.8; 20.2) of long-term disability and 6.9% (95% CI 6.1; 7.7) dependency in self care. Women were more disabled than men. The DFLE at age 60 calculated from the prevalence of needing help with Basic Activities of Daily Living (BADLs) was 16.4 years for men and 18, 2 years for women, compared to total life expectance after 60 which was 20.3 and 23.9 years respectively. This means that men are expected to live 4 years and women practically 5 years with different levels of disability. Men and women can, respectively, expect that 19% and 24% of their life expectancy at age 60 will be spent in a disabled state, but may expect only about 10% of their life expectancy to be spent unable to manage basic self-care activities of daily living; at least in this country (Jitapunkul, 2003).

Demographist did forecast this situation, but predictions even if they were frightening, they did not impact enough and societies did not react in accordance. Now in 2010 things are happening, we are facing the difficulties of not enough geriatricians, gerontologist, specialized institutions and geriatric hospitals at all. One reason is that medical students and residents are not motivated to choose geriatrics (Weiss, 2009).

Older persons still continue to be discriminated in hospitals (Hudelson, 2010), Elderly abuse is present (Daly, 2010) and caregivers are suffering from burn out (Courty, 2004).

To exemplified the two countries that are of interest in this work, a review of some statistics in France and secondly from Mexico are presented.

### 1.1.1 The French case

France has been by tradition a country known for its well being, the result is that its population ages well and gets very old.

In metropolitan France the estimated population is around 64 Million and 22 % from them are over 60 years old and 8.8% are over 75 years old (INSEE, 2010). According to the reports done by Robine at the institute of ageing, the ageing survival curve from France has shifted and has suffered a "rectangulation" phenomenon. This was caused by the decrease in early childhood mortality and the decrease in older age's mortality. For example, in 2007 there was a reduction from 1.3% in the mortality rate compared to the year before, mainly due to the female group over 90 years old. And at the same time they can be frail and die then more abruptly so that the shape of the demographic curve becomes acute (Robine, 2006). This phenomenon is also related to a theory already expressed by Fries (Fries, 1989) twenty years ago about the "compression of morbidity", and that he refreshed in the past years, explaining the role of co-morbidity. (Fries, 2005)

The reasons for this are well know. On one hand a better life hygiene that allowed the population to arrive at an elder age in better conditions. In 2005 with an average survival rate from 76.7 years, French lived one year more than the average European population which is 75.8 years. By January 2010 the French population was estimated at 62.79 millions. This natural increase reflects a big progression in the birth rate since 2006, but also from the augmentation in the survival rate, which is 77 years for men and 84 years for women. This means that in one year female did gain three and a half month of survival and men almost five months. Therefore if we look at the French population pyramid, there were at least 10 442 227 elders in January 2009. (INED, population et chiffres, 2010). And the fastest growing group are the oldest old (>85 years). This is important in terms of social security, assistance and budget. In January 2010 the number of centenarians was calculated at 14,944 persons (INED centenaires, 2010).

The more the person approaches the very old age, the more the person requires support of various kinds as in home assistance and this is related to the different degrees of handicap. In relation with these issues here are some predictive statistics from the INED.

- In France by 2050 the expected total population will be of 70 Million and 22.3 Millions will be over 60 years old.
- By 2015 there will be 2 millions of persons over 85 years.
- It must be assumed that the number of patients with Alzheimer's disease will also multiply by four. Nowadays they are about 800 000.
- To keep with the demographic growth between 5000 and 7500 new places in medical facilities are needed per year.

One major goal of the national health and social policies is to help keeping people at home, with the idea of preserving their autonomy, especially for individuals with some degree of dependence. Therefore knowing the DFLE is crucial. In a study done at the French National Institute of Demographics, it was estimated one decade ago, that two thirds of the expected life expectancy after 65 years were years with functional limitations and that 10% were years with restrictions in personal care activities but recently the results from a national study about handicap put into evidence that for people over 80 the degree of dependence relies mainly on physical disabilities but also a great percentage is due to cognitive problems (Do Santos, 2010).

In a European study using the DFLE as outcome the results compared to co-morbidity were the following. At age 65, men had a total life expectancy (TLE) of 15.3 years of which 12.1 years (79%) were free of any disability. Whereas women of the same age had an average TLE of 19.4 years, but only 11.0 years (57%) without disability. This puts into evidence the impact of gender on ageing. If we see the impact of comorbidity; men aged 65 years without stroke had 4.8 more years of TLE and 6.5 more years DFLE. For women it is slightly lower, 4.6 years of TLE and 5.8 for DFLE respectively. If we regard diabetes, men without this problem lived 4.4 years longer and had 4.1 years of DFLE. Women are more affected in this case, because they live 5.6 years more in general if they do not have DM (Jagger, 2007).

The importance of DFLE has been highlighted as a measure to adapt social and health policies and in developed countries trends in disability have been shown to be favourable like in France as mentioned by Robine et cols (Robine, 1982) but still the health systems are confronted to it. The costs are important either to the person itself or to their relatives and in a considerable part to the national health budget.

To exemplified this phenomenon using dementia as a tracer, in France the number of persons suffering from dementia over 75 years was 769 000 in 2003 and this number will increase faster taking into account that the rate of new cases diagnoses per year is 100 000 according to the PAQUID cohort study. Then we have to add the important costs for society in France, which were estimated at 7, 5 M Euros. Therefore the interest of using a new parameter called "Dementia Free

life expectancy". This concept was already proposed by the researchers involved in the PAQUID study (Ritchie, 1994) and in fact big investments on this field have been made. The actual French government supports an "Alzheimer's plan" that started in February 2008 and will go until 2012 axes: health, research and solidarity.

These priorities are also the main aspects for high expenses. One of the main reasons why these costs are so important in the field of health and solidarity is the necessity of different health personnel at home or at the institution. There are direct expenses generated either by the disease itself and or associated disorders like behavioural problems. These expenses are issued from medical visits and interventions, and also from other health care professionals at home and in the hospital, or institutionalization. In this part we integrate also the direct non medicalized expenses, corresponding to equipment and modifications of the habitat. And then, there are the "indirect" expenses: For example in Isère the region of France where this work was done, the persons can get some support according to their degree of handicap and help needed at home, this help corresponds to 21% of persons over 65 in France and 18% in the Isère department. From this budget around 90% is used for home interventions. In 2007 there were 1,2 million financial hours spent in these services. The cost of these services is around 20 Euros/hour and the APA takes in charge 15.99 Euros. Each region in France has a local institution dedicated to evaluate autonomy and decide the type of financial help that the person can get. Still the investments are increasing and in 2009 the budget for this help was from 124 Million euros (Perez, 2009).

The number of health care workers required to this type of tasks has also been estimated to be more important in two different groups; the persons with a physical handicap requiring assistance for some or all activities of daily living and secondly the persons with behavioural problems.

As commented above having a larger elderly population all over the world implies a huge effort for the society. Once again experts in demographics are concerned about one main issue. Who will care of all this old? (Robine, 2007). Health professionals try to analyse in their own regions the impact from dementia on the epidemiology of the phenomenon (Couturier, 1990).

First of all this issue concerns health policy makers, who need to be involved in a better planning of the social services allocated to this group. Second the pension or retirement policies and for sure the investment on funds for research on ageing have to be re analysed, especially regarding the new technologies that can help to keep persons in better conditions in their own homes.

The problem is that the term "disability" is an umbrella term for different levels of "needing assistance" in different tasks or aspects of daily life. Nevertheless it can also be quantified as the

proportion of dependence or handicap. Some definitions according to French statements (Mormiche, 2001) are the following:

Diseases (in the broad sense, i.e., including accidents and other mental and physical trauma and can be susceptible of medical treatment.

- Impairments denote any loss (such as amputation or sclerosis) or dysfunction of a body part (limb, muscle or organ) or of the brain. They generally result from a disease or trauma. A similar and more commonly used notion is "invalidity."
- Disabilities are a restricted ability, or a lack of ability, to perform normal activities or more complex ones. Normal activities include physical activities such as standing up, getting up, or walking up a staircase, and mental activities such as memorizing. Complex activities include dressing, using the telephone, and conversing with several persons. Disabilities are generally due to one or more impairments and these tasks are usually part of the standard geriatric assessment.
- Disadvantages is preferred by French-speaking specialists to the English "handicaps." Disadvantages denote a restricted ability, or a lack of ability, to accomplish a social role that the person may seek to perform or that society expects of the person. Such roles include attending school, doing work, communicating with other people.

Some statistics from about France and handicap (enquête, handicap-santé, volét ménages, 2008), this query recruited 28500 persons in two different years, 1998 and 2008. Included were adults from 20 years and over.

- There are >12 million people in France with one or more handicaps.
- 83% of persons between 60 and 79 years are can be considered even if 20% from this group says to have some difficulty with mobility.
- 59% from those over 80 years are considered relatively autonomous and 26,8% are moderately autonomous.
- 11,6% from the persons over 80 years are dependent this represents 227 000 persons, and from them 53% need help for at least one basic daily activity.
- 2.7% belong to the profile with complete dependence, this group of 62000 need to be assisted for most basic activities of daily living and two thirds are confined to a wheel chair or bed.

We fully agree with Bonvalet that there is a need to invest in the adaptation of the environment to keep older people in their home in France. She points out that older persons that are still

autonomous but sensible to their vulnerable status do hardly contact agencies in charge of adapting the environment at home (Bonvalet, 2009).

### 1.1.2 The Mexican case

Mexico has an estimated population of 106.7 million inhabitants and is at the 11<sup>th</sup> position worldwide and at the third position in America after the United States and Brazil. 50.8% of the Mexican population are women and 8.3% are over 60 years. The growing rate for this population groups is 3.52% compared to the total population growing rate of 0.86%. In 2008 life expectancy from birth was for a Mexican woman 75.1 years and for a man 72.7 years. The biggest subgroup of elderly are the younger-old (60-70 years) they represent 56.2% from all the persons over 60. Then the group between 70 and 79 years, represent, 29.9% and the 13.3% missing are those over 80 years old.

It is predicted that for 2015 there will be 11,8 Millions of older persons. The geographical distribution in the country is very irregular with zones like Mexico City with a huge density with 5871 persons/Km<sup>2</sup> and others like Baja California with 7 inhabitants / Km<sup>2</sup>(INEGI, 2006).

The social structure from the Mexican family is traditional nuclear and mostly children take care of their parents when they get older and loose autonomy. In 28% of Mexican households lives at least one person over 60 years old. But in some rural zones the children do migrate to the big cities trying to find a job so that their parents will be a new generation of elderly without children in their entourage to take care of them if needed. And for this future elderly population the use of technologies if they are cost effective, could contribute to a solution.

Data gathered in 2000 regarding disabilities show that from the total population with some degree of disability which is 795 000 persons, 41.5% were over 60 years old, representing the biggest proportion; and 52% were women. According to the type of disability:

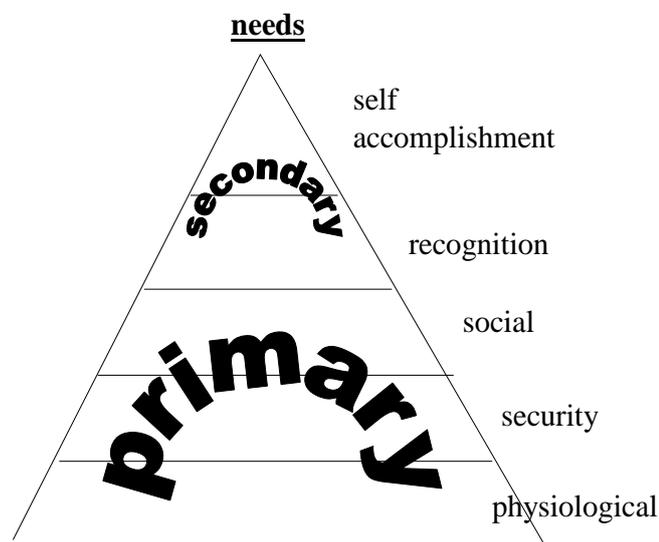
- 51% had motor function problems
- 30% visual problems
- 21% hearing problems
- 3.7% cognitive problems

Recently an analysis about the impact of diabetes on DFLE was done. Disability was assessed through a basic Activities of Daily Living (ADL) measure, the Instrumental Activities of Daily Living (IADL) scale, and the Nagi physical performance measure. Results indicate that diabetes reduces total life expectancy at ages 50 and 80 by about 10 and 4 years respectively. Diabetes is also

associated with fewer years in good health. DFLE (based on ADL measures) at age 50 is 20.8 years (95% confidence interval [CI]: 19.2-22.3) for those with diabetes, compared with 29.9 years (95% CI: 28.8-30.9) for those without diabetes (Andrade, 2010).

## **1.2. The loss of autonomy and ageing**

In this section a comment about what autonomy for the elderly population means is expressed after a reflexion about how it is evaluated or quantified and how ageing contributes to the loss of it. Therefore it is important to evoke the work done long time ago by Maslow fifty years ago (Maslow, 1954). He explained the different levels of needs that a human being has to accomplish to gain a certain quality of life. When talking about the elderly population the pyramid proposed by Maslow again has a central role. The three first levels from the base are fundamental to have an acceptable life and the upper two are important to achieve a complete well being. The main principle is that a human has to satisfy the first ones to be able to accomplish his life. But adverse events in life may cause a fall to a prior level (loss of job, accident, morbidity, etc...), and then the individual might need to recover to get back to the top. Elderly persons by definition are more vulnerable to remain at the top and many of them, in their better situation, may just fulfill the primary levels.



***Figure1.1 Maslow Pyramid, 1954***

But there are other ways of classifying and evaluating a group and we propose to use some definitions as applied in the International Classification of Functioning Disability and Health (ICF) from the WHO (<http://www.who.int/classifications/icf/wha-en.pdf>). Their operational definitions can be adopted in order to better evaluate a situation and cases. They are as follows.

Activity is the execution of a task or action by an individual.

Participation is the involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

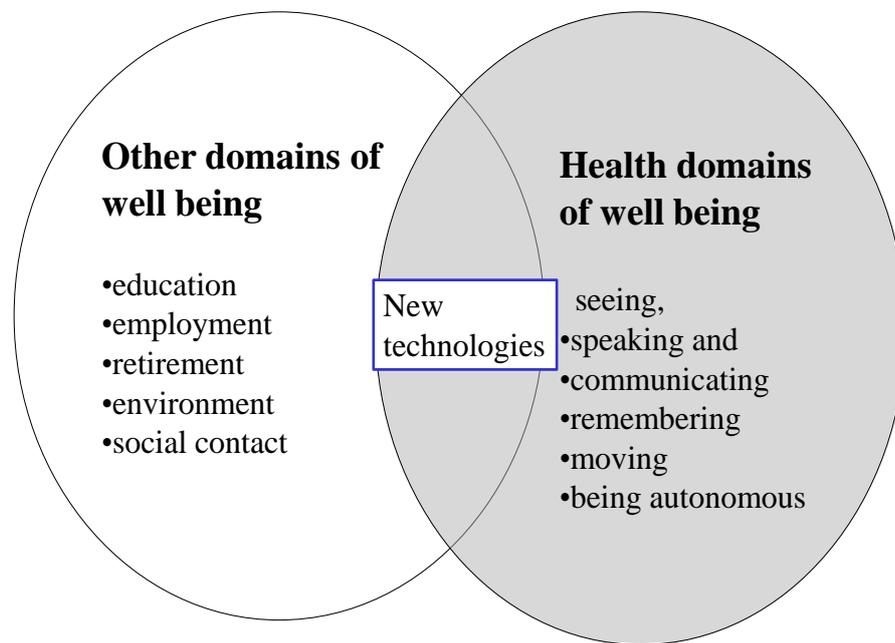
According to the ICF, the capacity qualifier describes an individual's ability to execute a task or action. This qualifier identifies the highest probable level of functioning that a person may reach in a given domain at a given moment. *Capacity* is measured in a uniform or standard environment, and thus reflects the environmentally adjusted ability of the individual. The environmental factors component can be used to describe the features of this uniform or standard environment.

Both capacity and performance qualifiers can be used with and without assistive devices or personal assistance, and in accordance with the following scale:

0	NO impairment (none, absent, negligible) -----	0 - 4%
1	MILD Impairment (slight, low) -----	5 - 24%
2	MODERATE Impairment (medium, fair) -----	25 - 49%
3	SEVERE Impairment (high, extreme) -----	50 - 95%
4	COMPLETE Impairment ( total) -----	96 - 100%
5	Not specified	
6	Not applicable	

Another model of wellness proposed in the ICF more recently is the following. Well-being is a general term encompassing the whole universe of human life domains, including physical, mental and social aspects that make up what can be called a "good life". Health domains are a subset of the domains that compose the total universe of human life. This relationship is presented in the Figure 1.2. There is not a fixed boundary between the domains. We propose that *Innovative*

*technologies* can be a link to keep these domains in a better harmony according to the level of deficiency in each of its components.



**Figure 1.2 Adapted from ICF, WHO publications**

Elderly persons prefer remain as long as possible in their own home (Oswald, 1994). This author interviewed 84 elderly living at home with a mean age of 77 years. He did focus on one hand on the general meaning of home and on the other on specific sections of the home environment like most favourite place within the home, favourite meaningful things. The results revealed that the meaning of home is similar independently of the functional capacity. In the experience of the most favourite place at home, subjects suffering from mobility impairments are tending more to an environmental "centralization" than healthy subjects do. This puts into evidence the importance of the environment seen by the user or person. This point is crucial if we take into account that sometimes little can be done to modify or help the person, so extrinsic factors related to their well being like environment can offer a solution. In geriatrics and gerontology we have a better and holistic view of what autonomy can mean to the elderly person itself and their entourage as well as their integration to the community. For us geriatricians, autonomy is one of the main variables we evaluate to get a better idea of the individual in his microenvironment at home and then his role and interaction within the community or society.

But this point was already stated long time ago by Katz who first published his Index of Independence in Activities of Daily Living, which is still in use today (Katz, 1970). And we do emphasise his positive point of view when scoring "independence" level and not the contrary. This index is based on common sense and observation and has been validate in many different populations.

The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the person's ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The Index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Persons are scored yes/no for independence in each of the six functions. A score of 6 indicates full function, 4 is moderate impairment, and 2 or less indicates severe functional impairment (see annexe 2).

And then we have the complementary scale of Instrumental Activities of Daily Living (IADL) from (Lawton, 1969) (see annexe 3).

Their use is widely spread because both scales have proven to be an important tool to evaluate autonomy. It is important to stress that scales also need to be modified according to the introduction of new technologies of general use. One good example is the use of telephone. The item in the Lawton scale about it says:

A. Ability to use telephone

1. Operates telephone on own initiative; looks up and dials numbers.
2. Dials a few well-known numbers
3. Answers telephone but does not dial
4. Does not use telephone at all.

But this item also evaluates indirectly other functionalities or capabilities of the person. For example before the availability of wireless or cellular phones, the person did also have to do the transfer to get where the phone was, also implicating that the person could hear the ringing even if not being nearby. In a simple way this task helped evaluate: hearing, orientation, memory, mobility and praxias.

It is truth that with the introduction in society of hand free and cellular phones then one part of the functional evaluation of this item is lost but the complexity for most elderly of the use of new

technologies again can test other capabilities. It means that before a person answers the phone he did have to get up and go the room where it was connected. Then with hand free devices one could have the telephone closer like cellular phones. But for the moment we will still focus on the global evaluation of autonomy in this chapter. This comment was to exemplify how with a simple question we can get a lot of information about the person's autonomy or performance.

Another reason why IADLs can be so important is that they do not tell us only about their capacity to perform a task itself, but indirectly also about the health status of an individual. We count with some good studies that show that especially for the elderly population the performance of IADLS and ADLs are the only physical activity that they do. It's useless to explain the benefits of physical activity here, but to be more objective about what IADLS mean in terms of energy expenditure using METs (Metabolic expenditure units) we present this reflexion. 1 MET is equivalent to 3.5 ml of oxygen per kilogram body weight per minute, a unit well known by cardiologists. Some household activities and gardening activities are assumed to involve considerable amount of energy expenditure (e.g. vacuuming, lawn mowing) and have been recognized for representing moderate-intensity physical activity of 3.0-6.0 METs (Ainsworth, 1993).

Recent developments involving a small but growing number of measurement studies of energy expenditure associated with domestic tasks have demonstrated that household activities can be measured and validated with precision with some domestic activities being performed at moderate intensity for health benefits (Welk, 2000). In general to get cardiovascular benefit persons have to have an activity around 5 METs. If we translate this to IADLs, this would mean that a person that can do the vacuum cleaning or gardening at least 4 days a week would be someone in good shape. So, as it will be explain in chapter 3 measuring daily activities can be done with accuracy through an intelligent environment.

And on the other hand the lack of activity is deleterious as proven by Monda et cols. who studied a large population of almost 10 000 persons between 18 and 55 years over nine years in China. They concluded that there is a tendency to gain weight. In general the Chinese population ages very well, they do have a good activity level and before the social and economical opening they were not suffering from overweight as a health issue like in other countries. So overweight due to a modified lifestyle is a reality in emerging countries (Monda, 2008).

What regards Mexico, unfortunately after the United States it has the second place in obesity, due to the unhealthy diet mainly and the lack of physical activity (WHOSIS). Over 70% of the total population suffers from overweight according to the national health survey (ENSALUD, 2006). The costs in 2008 for direct and indirect causes related to obesity where of 2732 Million US dollars and a (salud.gob, 2010).

So obesity and its related disorders are a negative factor that diminishes autonomy and that has become a great burden in public health concerning also the older population. It is important to recall that technologies can contribute to diminish energy expenditure and by this means promote overweight with all the adverse consequences for health. A person who ages with a low activity level and with overweight will certainly have more risks to develop co-morbidity and become frail. But not only at home we see this phenomenon; the use of technology at work can be partly responsible to reduce energy expenditure and contribute to the obesity phenomenon (Lakdawalla, 2009).

There is a need to find a balance between the benefits and risks of the use of Innovative Technologies. The main goal is to focus the use of technology for fastidious, dangerous or repetitive tasks and keep the persons performance physically and mentally as much as possible. Therefore it is crucial to evaluate autonomy and handicap correctly.

Katz and Lawton did focus on quantifying independence but for policy makers and health statisticians the impact is on cost benefit. They prefer to quantify handicap or dependency! So the term handicap has more impact on the society and politics, therefore the level of functionality in this field is measured in these terms.

From an epidemiological perspective it is very important to have reliable data about the level of functionality of a population. These data can be very valuable to design and guide future development in different fields: when you know where is the problem you can start fighting against it.

It was mentioned above that the French population has a wide life expectancy but how well do they do? According to a study done by Robine et cols; in which they studied self reported activity level in people over 55 years, they found that 50% reported having functional problems and 20 % needed some help in personal care and restrictions were more likely after 70 years (Robine, 2006).

In geriatrics therefore a way to combine some of the variables that deal with loss of autonomy and physical activity related to co morbidity are better assembled in a geriatric syndrome called frailty. In the coming section, the relation between frailty and the variables studied in this work are explained.

### 1.2.1 The loss of autonomy and frailty

The term frailty is used to describe older persons at high risk for adverse health outcomes. In 1997 Woodhouse and cols defined frail elderly people as those more than 65 years old of age who depended on others for the activities of daily living and were often under institutional care. (Woodhouse, 1997). Frailty has been equated with functional dependence in the ADLs although this phenomenon can be also predominantly be explain in medical terms (Cochen, 2009).

In 2001, Fried et al. proposed a now widely cited definition which suggests that frailty is a clinical entity related to, but distinct from, ADL disability and co morbidity. Frailty is evident over time through an excess vulnerability to stressors, with reduced ability to maintain or regain homeostasis after a destabilizing event (Woodhouse, 1997).

Frailty status can be identified based on the presence of any three of the following five characteristics according to this model.

- shrinking,
- weakness,
- poor endurance,
- slowness,
- low activity.

In a study done in Canada with 740 community -dwelling seniors, using the operational definitions from Fried's criteria for frailty, they found that among those classified as frail, 29.1% had disabilities in ADLs, 92.7% in IADLs and 81.8% had comorbidity. Frailty was associated with age, sex, income, education, number of chronic diseases, ADL disability, and IADL disability. Findings on the relationship between frailty and socio demographic variables, morbidity and disability, support previous studies, providing further evidence that although frailty seems to be a distinct geriatric concept, it also overlaps with other concepts (Wong, 2009). Therefore deficit accumulation is still a keyword (Song, 2010). Frailty is a geriatric syndrome well recognized and so vast that researchers try to find a better way to recognize it, for example through biomarkers (Walston, 2006; Zerky, 2008).

It is out of the scope of this work to make a deep analysis on frailty, the purpose is mainly to use some of the outcomes measured in frailty studies in relation to the type of outcomes we measured, mainly activity and further more nocturnal activity. But co morbidity is a main factor for frailty (Newman, 2008).

Whatever from which approach we study this phenomenon, the goal is to recognize those "frail" subjects in order to try to prevent a rapid decrease in autonomy. For example, using the data from the "Three cities cohort" it was found that there were some risk factors for mortality in this extreme case. 91% of persons that die were over 65 years old and 35% were living at home. After a case control analysis it was found that the social level, degree of autonomy, co-morbidity for cardiovascular, neurological or psychiatric diseases as well as the quality of the habitat were the most relevant factors related to the risk of mortality (Institut Veille Sanitaire, 2004). And concerning

the Mexican case, according to the characteristics of the population an index was developed having as outcome like in most studies mortality. Over 4000 subjects were studied and the index did show to have a predictive value (Garcia-Gonzales, 2009).

### 1.2.2.The loss of autonomy and dementia

All over the world the prevalence of dementia has been estimated around (8%) and according to the World Health Report, dementia accounts for 2% of years of life lived with disability, being ahead of other chronic diseases, such as cerebro vascular disease and diabetes mellitus (WHO report, 2001).

But dementia is a wide term and over 20 years ago the main definitions were based on the cognitive level. Dementia is the decline in the memory and other cognitive functions in comparison with the patient's previous level of function as determined by a history of decline in performance and by abnormalities noted from clinical examination and neuropsychological tests. Most operational definitions used in protocols are those proposed from NINCDS-ADRDA (National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer's Disease and Related Disorders Association) work group from 1984 (Mc kahn,1984) and their further revision (Knopman, 2001). Dementia, not unlike heart failure or renal insufficiency, is a generic term that makes little assumption about etiology. Recently a German group has opened the debate around the concept of dementia, proposing that this term should be reframe or replace. And one of their main arguments is from an ethical point of view, because nowadays in memory clinics patients are given the "label" of dementia when they are still at early stages and are still capable of being autonomous and doing many things (Kurz, 2010). The term of dementia is pejorative then literally it originates from the Latin words "*de mens*" meaning absence of mind. So this debate is an open question. But once a person has been diagnosed with any type of dementia the immediate action should be to find out at which stage the person is and especially to evaluate his capabilities and autonomy in order to better plan interventions.

Worldwide, the most common type is Dementia of the Alzheimer's Type (DAT) as stated by Alzheimer's international in 2008. The number of cases was around 30 million and they calculate that yearly 4,5million of new cases are diagnosed. This frightening numbers will increase to 100 million cases by 2050 according to predictions (Ferri,2005). In Mexico the prevalence varies around 4 % depending on the region, but a survey made in the metropolitan area of the capital revealed a prevalence of 4.7% (Gutierrez-Robledo, 2001).

The real challenge arises among the elderly, in whom dementia is also far more common. This is because the elderly tend to have less demanding daily activities and when these are affected the

phenomenon is more difficult to detect .The presence of dementia should be suspected whenever mental changes of insidious onset emerge without sufficient situational stress and gradually interfere with the daily living activities that are appropriate for age and background. Dementia can be reversible or irreversible, precipitously progressive or indolent, bristling with multiple cognitive deficits, or characterized almost exclusively by disturbances of affect, motivation, and personality (Mesulam, 1985).

Even if many molecular and biologic markers have been found and the physiopathology has been more elucidated, showing the major roll of B amyloid, the tau, neurotrophin, neurotransmitters and mitochondrial dysfunction between others (Querfuth, 2010) there is not one specific laboratory test to diagnose Alzheimer's disease, so it still relies on clinical criteria and neuroimaging.

A longitudinal study measuring the volume of the hippocampus through IRM showed that after 72 years accelerated atrophy starts, which is in relation with the risk of cognitive impairment (Zhang, 2010).

So if we say that we need to do a diagnosis the sooner the better, then we need the infrastructure required. For example for the delay in the diagnosis, we cannot compare between France and Mexico, because of the differences in the social security system. In France, according to a survey done in 2009, it was shown that if a person contacts the security system branch to be informed about what to do with his relative who complains from memory problems then the answer can vary. For example in the department or county Isère, the delay is 3 months to get a first contact visit with a "memory center". But in other French regions the delay can be longer (Suret, 2009 ).

Until now on daily basis the diagnosis has advanced mainly due to neuroimaging and more specific neuropsychological tests, then biomarkers have shown to be specific only for some type of very specific type of dementia like Huntington. Another issue that has been argued about the presence or absence of a biomarker is from an ethical point of view. Should patients be screen for biomarkers that will tell them that they have 50% chance to develop DAT? Is it a responsibility from the physician? Or should the physician screen only if the patient himself demands it?

This point is an open question that will not be further treated but was important to express it.

Therefore biomarkers are mainly used in research studies like the presence or absence of Apolipoprotein E4 or tau levels in order to better follow up the effect of some drugs. In those cases there is a specific objective and it was first discussed with the patients and families. Also from a practical point of view the main goal to establish a most accurate diagnosis about the type of dementia is for therapeutic reasons. Nowadays there are worldwide four molecules that are commercialized and that have proof to be effective by retarding the evolution of dementia. Some

are more adapted for later stages other might have more impact on behavioral problems. But their effectiveness is also limited and a combination of them have been also proposed for specific cases. (Querfurth, 2010). Memantine has the authorization to be used in combination to anticholinesterasic agents especially for the treatment of severe cases and those with behavioral problems (Puangthong, 2009).

There are other types of dementia that also have increased in attention to the medical community, like vascular dementia and dementia of Lewy Body type and affect also the circadian rythm (Harper, 2004). Fronto temporal dementia is less frequent but also very important regarding the presence of behavioural problems.

But regardless of the etiology of dementia, once the patient is in a moderate to severe stage they do *a grosso modo* dysfunction in the same way. Therefore when a geriatrician is in front of a patient with a moderate to severe dementia what he needs to know is the patient's level of autonomy in order to adapt a strategy. This includes a combination of medical therapeutics and non medical interventions. In order to do so the clinician can use the multiple screening scales done for patients with dementia.

### 1.2.2.1 Evaluating autonomy in dementia

Since the most common type of dementia is DAT, most scales were validated for it. For example the Global Deterioration Scale was validated by Reisberg et al. against behavioral, neuro anatomic, and neurophysiologic measures in patients with primary degenerative dementia, meaning DAT. It includes besides cognitive values, also some IADL items like capacity of paying bills, or planning a dinner but also dysfunction in ADLS are scored for later stages like capability of dressing, toileting, continence and motor function. The reason for including IADL, is because to complete or do them the person requires a competent memory and intact executive functions. The last ones are complex cognitive abilities that enable an individual to perform tasks that include: planning, problem solving, anticipation of possible outcomes and inhibition of irrelevant processing (Lezak, 2004). We can see that this clinical staging scale is still valid but it does not tell us about some other important abilities like eating. Another widely used scale is the CDR (Clinical Dementia Rating) this scale is more general, even if it was developed for persons with DAT it can also be used to stage other types of dementia as well. The Clinical Dementia Rating or CDR was developed at the Memory and Aging Project at Washington University School of Medicine in 1979 and is still a very valuable and used instrument. Reisberg commented about the utility of the scale in different domains (Reisberg, 2007).

The Clinical Dementia Rating is a five-point scale in which CDR-0 connotes no cognitive impairment, and then the remaining four points are for various stages of dementia:

CDR-0.5 = very mild dementia

CDR-1 = mild

CDR-2 = moderate

CDR-3 = severe

These scores are given in six domains: 1) memory, 2) orientation, 3) judgment and problem solving, 4) community affairs, 5) home and hobbies and 6) personal care.

It can also be adapted from information recalled from a medical record, so that it permits us to have an idea about previous stages or performance in the past.

Table.1.1 Reisberg scale , 1982

STAGE	LEVEL OF FUNCTIONING	CLINICAL DIAGNOSES
1	Normal decrement	Normal adult
2	Subjective deficit in word finding	Normal aged adult
3	deficit in demanding employment setting	Compatible with incipient DAT
4	Assistance required with complex tasks ( handling finances)	Mild DAT
5	Assistance required in choosing clothing	Moderate DAT
6A	Assistance required in putting on clothing	Moderately severe DAT
6B	Assistance in bathing	
6C	Assistance required with the mechanics of toileting	
6D	Urinary incontinence	
6E	Fecal incontinence	
7A	Speech ability limited to approximately a half-dozen words	Severe DAT
7B	vocabulary limited to a single word	
7C	Ambulation lost	
7E	Ability to sit up lost	
7F	Consciousness lost	

This is important because we can situate the person or patient in a previous level gathering information mainly from the family or care givers. So that retrospective studies can be done thanks to it. The questions are either answered by the patient himself or the caregiver and if needed data is gathered from medical records.

There is an algorithm to calculate the total score of the global CDR, but a new version has been developed. The CDR-SOB (Sum of Boxes Scores), this version correlates well with the global CDR score for dementia staging. Owing to the increased range of values, the CDR-SOB score offers

several advantages over the global score, including increased utility in tracking changes within and between stages of dementia severity. So it can be used for the follow up in an appropriate way (O'Bryen, 2008).

Table 1.2 CDR Sum of Boxes Range Staging Category

0 Normal
0.5-4.0 Questionable cognitive impairment
0.5-2.5 Questionable impairment
3.0-4.0 Very mild dementia
4.5-9.0 Mild dementia
9.5-15.5 Moderate dementia
16.0-18.0 Sever dementia

So again this scale can be very broad, they give us a global level of autonomy but do not tell us more about specific tasks like eating and behaviour. But there are other scales that are more specialized and focused on specific problems like, delirium, agitation and behaviour as will be mentioned further.

But in general the main issue that concerns nowadays physicians, family members and care givers is not the memory problem itself. The cognitive impairment due to dementia is for sure a great burden for the person and family at the beginning but once the disease gets worse two major problems appear: *autonomy loss and behavioural symptoms*. These points are a key to decide when a person is still capable to stay at home or not, mainly because the patient becomes difficult to handle.

In a population study done in several countries with low and medium incomes, where Mexico did participate, it was found that, dementia, not blindness, is overwhelmingly the most important independent contributor to disability. And also when analyzing the data from 4182 subjects over 65 years, it was found that: 70% of the participants had a low education (<5years) and that 3.3% of them had cognitive and functional impairment (Mejia-Arango, 2007). This shows that dementia is not a disease typical from reach countries. Therefore in countries like Mexico where the access to the treatment for dementia is restricted for a minority the burden is greater.

Since the main issue in this section is autonomy and risk factors that influence it we introduced another variable, which is a major risk factor for dependency and caregiver burn out and also a

cause of institutionalization. Behavioural problems have become so important that they are now recognized as a separate problem to treat.

### 1.2.3. BPSD (Behavioural and Psychological Symptoms of Dementia)

The new terminology BPSD (Behavioural and Psychological Symptoms of Dementia) is now recognized as a related syndrome that can be evaluated and treated separately. But still a discrepancy between different ways of classifications exists. As published in the consensus of severe dementia, BPSD are a core feature when taking into account the International Classification of Disease, but it is not the case when using the Diagnostic and Statistical Manual of Mental Disorders DSM IV. Over 90% of people with dementia develop behavioral problems or psychiatric symptoms at some point during their illness (Ballard, 2001).

Many authors have shown that the different types of behavioural problems are in relation to the degree of cognitive impairment or dementia from different types. Trying to understand this phenomenon is therefore of a capital importance and knowledge about the neuropathological bases is relevant (Cummings, 2005; Holtzer, 2003). This can be an evidence base for the use of some new treatments in order to enhance the quality of life of patients and caregivers, then it has been proof that caregivers burnout is one of the main factors to decide placement of a patient presenting BPSD. Especially for those caregivers of patients that are at home (Arbus, 2010). But also in the hospital the consequences of BPSD are important (Wancata, 2003). In France at least 80% of patients with dementia are living at home and only a percentage of them can benefit from health professionals that come to their homes (Vellas, 2005). Another main goal is to avoid as possible the use of antipsychotics that have shown just a modest effect compared to adverse events (Liperoti, 2008).

#### 1.2.3.1 Common types of BPSD

Aggression has been reported by carers of 4 % of persons with mild dementia, 14 % of those with moderate dementia and up to 42% of those with severe dementia and special scales have been developed to quantify this symptom (Patel, 1992; Hall, 2004).

Agitation is also a common behavioral problem that will appear in some stage of the disease (Deutsch, 1991).

Anxiety is also a relevant problem in patients with dementia and did not receive much attention until recently (Shankar, 2000). The prevalence of this symptom varies from 5% to 21 % (Robinson, 2007). In fact anxiety is more common in individuals with dementia than without it (Cummings, 2004) and Anxiety is associated with:

1. Worse quality of life
2. Problem behaviors
3. Limitations in activities of daily living
4. Nighttime awakenings
5. Poorer neuropsychological performance

The presence of anxiety in patients with dementia has been associated with future nursing home placement, meaning probable caregivers burden, and having psychogeriatric problems is a risk factor for frailty (Pipers, 2009).

But one of the difficulties is to differentiate symptoms from dementia and anxiety because they may overlap. For example in Generalized Anxiety Disorder (GAD) the persons may present: restlessness, difficulty to concentrate and be easily fatigued, and those symptoms can also occur in dementia. The core symptom which is excessive anxiety or worry that is difficult to control, cannot always be assessed in patients with dementia. Again the DSM-IV provides general guidelines.

Some instruments are designed to the assessment of neuropsychiatric symptoms in dementia. I will just comment that the BAHVE-AD (Reisberg, 1996) comprises an anxiety domain with four items: anxiety regarding upcoming events, other anxieties, fear of being left alone and other phobias.

The NPI (Cummings, 1994) comprises 10 domains, with a later version adding two others in 1997. Symptoms are assessed for at least 30 days and as the BEHAVE –AD the NPI is based on the interview with the caregiver. For each domain, the NPI begins with a screening question, followed by seven or eight more specific questions. For example for anxiety, the specific questions are: worrying about planned events, feeling shaky, unable to relax, shortness of breath or gasping, butterflies in stomach, avoidance of certain situations, becoming nervous when separated from caregiver.

Continuing using anxiety as example, good interrater reliabilities have been reported for frequency (93,6% agreement) and severity (100% agreement) while test retest reliabilities range from 0.64 to 0;71 ( Cummings, 1994).

The problem for example with the NPI is that due to its length and application time (15 min or more) and its reliance on the clinician to complete the caregiver interview makes it not very practical for general medicine settings, where most of the personnel are overwhelmed with work or in acute care settings where health care personnel changes more often.

So therefore this can be an argument in favor of using new technologies to evaluate in a more objective way, patients with this type of behavioral problems. A main advantage is that environmental technologies are fix and stable and do not need to be calibrated by personnel and are non invasive for the usual medical procedures.

But coming back to the presence of behavioral symptoms, a careful evaluation needs to be done to differentiate them from the possible presence of an acute confusional state also known as delirium. This means that some elderly without dementia may present one or more of these symptoms and once the underlying cause is resolved, a cognitive evaluation can tell about the real cognitive status from the patient. Further in chapter 5 a broader analysis illustrated by a case report will explain this situation.

#### 1.2.3.2 Delirium or Acute Confusional State

Delirium is a common disorder in geriatric patients. It is an active phenomenon that is more common seen in emergency rooms. It is characterized by the abrupt appearance of symptoms and it can last from several days to several weeks. One classification divides delirium into three subtypes, based on different symptom patterns, i.e. hyperactive, hypoactive, and mixed presentations of delirium (Lipowski, 1983). Hyperactive patients are restless, agitated and often suffering from hallucinations and delusions. Hypoactive patients appear lethargic, drowsy, sedated, respond slowly to questions, do not move much and are often misdiagnosed as being depressed. Patients with the mixed subtype have symptoms of both types.

In order to diagnose delirium and to assess its symptom profile and severity, many different instruments have been developed both for clinical and research use. The most frequently used scale for diagnosing delirium is the Confusion Assessment Method (CAM) (Inouye, 1990). It is well accepted by other health professionals besides physicians. The CAM is composed of two parts. The first one is an assessment instrument that screens for overall cognitive impairment. The second one includes only those four features that were found to have the greatest ability to distinguish delirium or reversible confusion from other types of cognitive impairment.

Validity/Reliability: Concurrent validation with psychiatric diagnosis revealed sensitivity of 94-100% and specificity of 90-95%. The CAM significantly correlated with the Mini-Mental Status Examination, the Visual Analog Scale for Confusion and the digit span test and the presence of delirium is correlated to unplanned hospitalizations (Inouye, 2008).

The emphasis we give on these evaluation scales is that nowadays we still do have some trouble trying to identify patients that do present with behavioural problems that can be classified initially as having delirium. This happens mainly if the problem persists over several weeks or if it has an intermittent pattern. Recently a review on persistent delirium showed the relevance of the problem to define it according to duration. This problem is accentuated when it appears superimposed to dementia. Another characteristic is the changing history of the phenomenon (Boettger, 2009).

These clinimetric scales are usually used in emergency departments or acute care units, the diagnosis is mainly clinical and the presence of and underlining organic disorder helps to the correct management. A confusional state is always related to activity, as it was indicated by the above classification into hyper or hypo active type. In this means we can see the utility of measuring this parameter to better follow up the evolution when using actigraphy. Indeed the measure of activity can be useful for the follow up, of these patients and very useful for patients presenting the hyperactive type.

Another important aspect is that Delirium can be superimposed to dementia which makes the treatment more complicated if not recognized. This is a phenomenon more and more recognized and its prevalence ranges between 22% and 86%, being the highest rates in units in charge of surgical patients (Fick, 2008).

For example scales can be useful for outcome evaluations combined with actigraphy. In a study of ten elderly subjects with severe dementia, they were given bright light (5000-8000 lux) for 45 min each morning for 4 weeks. Two rating scales of behavioral symptoms in dementia were used as outcome measures: Cohen-Mansfield Agitation Inventory (CMAI) and Behavior Pathology In Alzheimer's Disease Rating Scale (BEHAVE-AD), a scale for sleep-wake disturbances, and actigraphy to monitor activity rhythm. Behavioral symptoms improved with treatment. No changes in sleep-wake measures were found. There was an advance of the activity rhythm acrophase during treatment. These results suggest that short-time bright light improves behavioral symptoms and aspects of activity rhythm disturbances even in severely demented subjects (Skervje, 2004). This is an example of the utility of actigraphy in the follow up of behavioral problems and also the effectiveness of a therapeutic intervention. This is a real challenge in geriatrics or psycho geriatrics. For example quantifying agitation has been a marker for the follow up of patients with BPSD and delirium. But agitation is a symptom that is mainly related to enhanced activity, therefore the assessment has been widely studied through scales (Cohen-Mainsfield, 1989 and 1996). So the idea for the coming work is also to show that clinical scales do exists and are useful but that technology can support them through more quantitative values and therefore giving health personnel a valuable aid.

## **1.3 Sleep features in the elderly**

In the last decades sleep has become a matter of interest for researchers, not only because a human being spends in average a third of his life sleeping, but also because studies about sleep can give important information about the health status of a person.

### **1.3.1 Normal subjects**

One of the main reasons for trying to understand the circadian cycle changes due to ageing is to better make the differences between a normal sleep pattern and a pathological one. Especially related to some type of disease that can also be part of the ageing process, as for example dementia. This phenomenon is common in geriatrics and it can be rather complicated in some cases to elucidate between ageing and disease.

In resume, sleep consist of two main phases; Rapid Eye Movement (REM) sleep and Non- REM sleep which is again divided in three deeper stages; N1,N2 and N3. Older adults spent less time in deeper stages.

There exist four major modifications related to sleep and the circadian rhythms that are directly modified with the ageing process.

- 1) the amplitude of their rhythms reduces
- 2) the phase of the circadian rhythms becomes earlier
- 3) their natural free-running period ( $\tau$ ) shortens and
- 4) their ability to tolerate abrupt phase shifts

To explain them we can tell that human beings have circadian pacemakers, that in advanced age have accumulated a lot of circadian cycles, which can explain that they are very stable and suffer just few changes through life, but this modifications can be seen as function of ageing per se, rather as a function of the pathologies concerning older people (Ancoli, 2006).

With the ageing process sleep patterns change. The amount of sleep obtained by the elderly is undoubtedly less than that obtained by the young. Healthy elderly can spent much more time awake as younger adults (Bliwise, 1993) which can be a source of distress and then make them consult their general physician, who in most cases will prescribe a sleeping pill. Older subject have a higher

tendency to multiple awakenings during the night period but they do not fall asleep soon, so the perception of freshness from these awakenings does not exist compared to younger adults, and this has a negative impact on sleep quality (Zilli, 2009).

Having said so, we can analyse one important variable concerning the circadian cycle which is light exposure. Its implication as a "photic zeitgeber" in humans is the likelihood that that light information flows to the CNS (Central Nervous System). This phenomenon is already attenuated in elderly once the lens gets thicker (Hofman, 2000) and this effect can be exacerbated due to the way of living of some adults that do not profit enough from daylight, especially during the short winter days in some countries. It is important to recall that the eye is not only a visual organ but a main sleep or circadian rhythm regulator. There is still a lack of information from patients and physicians about the modifications of sleep according to age. Then we can add the societal rules that also play a role while trying to organise people's day/night activities. And for the special case of people that are in nursing homes or other structures, sleep habits can be perturbed, while forcing residents or patients to follow "in house rules". For example in a nursing home or at the hospital where patients are being "put into bed" most of the times very early in order to cope with the lack of personal and the staff activities. Then we favour the long periods of immobility or reduced mobility in bed. When a person/patient wakes up too early in the morning and cannot sleep anymore, then the person is sent back to bed. According to medical staff appreciation in these cases, they might register a "bad night" in the patients file and this will encourage the unjustified prescription of hypnotics, instead of improving sleep hygiene.

In general the most common complaint is "insomnia". The elderly are particularly affected with a prevalence of around 30%. In "The National Institute on Aging's Established Population for Epidemiologic Studies of the Elderly" (EPESE) study, they showed that 42% of the community dwelling seniors that participated, did complain of having difficulty falling and staying asleep (Foley, 1995). Sleep disturbances were more common in persons with physical disability, depressed mood, respiratory symptoms and fair to poor perceived health. Among almost 5000 participants who denied having symptoms of insomnia at the beginning 15 % reported symptoms at the end of the three year study, suggesting an annual incidence of 5 % in this group of population. In general the incidence between men and women is similar, but in subjects over 85 years it seems to be more frequent in men.

Depressive symptoms are a special problem, because some authors have stated the causative disorder of insomnia in major depressive Disorder (MDD) and on the other hand between the persons suffering from severe insomnia in the EPESE they found that 37.4% had psychiatric disorders and 21% had depressive symptoms compared to 9.9 and 3.7% in persons not reporting

insomnia (Foley, 1995). This is still valid, somatic co-morbidities associated with aging are known to be risk factors for both insomnia and depression. In patients with depression the monitoring of insomnia is required (Nicolas, 2010).

#### 1.3.1.1 Circadian rhythm sleep disorders (CRSD) in aging

Optimal sleep quality is achieved when the desired sleep time coincides with the timing of the endogenous circadian rhythm of sleep and awake propensity. CRSD appears from alterations of the central clock. Although the primary cause of CRSD is a disruption of the circadian timing a combination of physiological, behavioural, and environmental factors influence the clinical presentation; clinically speaking this means the presence of relatively normal sleep that occurs at abnormal times.

In the case of Advanced Sleep phase disorder sleep commences and ends at unusually early times; in the case of the "Irregular Sleep Wake Disorder", as its name says the person sleeps in disperse way across the 24-hour day.

When discussing moving from amplitude to phase there is a consistent evidence for an age-related phase advance, this means an earlier phase in the timing of the CNS. This phenomenon has been proved through different markers for circadian rhythms like: melatonin and cortisol levels, blood pressure, levels of neutrophils and lymphocytes, as well as some element like iron and magnesium (Hofman, 2000). With ageing there are also some profound changes in overall activity levels that can be interpreted as a reduction in the amplitude of the rest/activity rhythm, which may affect the circadian cycle and sleep (Monk, 2005).

Disturbed sleep is also associated with impaired memory and attention and can be misinterpreted as signs of dementia. But dementia itself depending on the type of dementia can also present sleep disturbances and this merits a special section.

#### 1.3.2 Sleep features in dementia

Dementia is characterized by cognitive decline and behavioural problems and also by disturbances of the sleep-wake rhythm. Precisely these problems can be a major burden for the caregiver. Although patients with severe dementia are sleepier throughout the day and night than those with mild-to-moderate dementia all of them have very disrupted sleep (Bliwise, 2009, Martin, 2000).

### 1.3.2.1 Parasomnias: REM Behaviour Disorder (RBD)

This group of disorders are undesirable non deliverable physical or emotional events that occur during sleep. The majority of cases occur with advancing age. They mainly appear while starting sleep or at the end while arising but also appear from specific sleep states, such NREM and REM.

Abnormal movement may be an important part of it, emotions and perceptions, dream enactment and autonomic activity that occur during sleep or are associated with arousal. Typical manifestations of these disorders are:

- enuresis,
- night walking,
- night terrors,
- dream anxiety attacks,
- nocturnal complex seizures.

There is a potential risk of injury for the patient himself or the bed partner.

RBD needs several test to be diagnose: Polysomnography shows intermittent loss of REM sleep-associated muscle atonia and the patient manifest violent motor activity. This type of problem has been related to conditions like: Parkinson's disease, progressive nuclear palsy, Shy-Drager Syndrome, multiple atrophy and brain stem AVC and all these entities area associated to dementia or better say dementia is part of the stages of these diseases.

One of the main problems in this situation is to find a more precise tool to survey these problems. There exist many different clinical scales to measure the degree of these problems, but most of them rely on the subjective appreciation of the persons. This has the inconvenience that there will be always a margin of error and that different observers may quote differently.

Measuring activity has been proposed as a good marker of different health situations. To use innovative technologies two situations are crucial, first be aware of the advantages and disadvantages of the new technologies and second to know exactly the different profiles of groups of elderly that could profit from it. Therefore the participation of geriatricians and other professionals in gerontology in the development of new technologies is mandatory.

In this section we want to propose a perspective of targeting different groups of older persons according to different technologies.

To better understand the need of the population targeted, we need to divide it into different groups. Measurements of sleep in patients with dementia have shown:

- increased sleep fragmentation,
- longer sleep onset latency,
- decreased sleep efficiency,
- decreased total sleep time, and
- decreased slow wave sleep (Ancoli,2005).

In addition, those with more severe dementia appear to have more severe sleep disruption. In a recent study they found that seventy-one percent of the participants with dementia and 55.7% of control participants had sleep disturbances ( $P=.001$ ). Most frequently reported in the mild dementia participants were insomnia (29.9%), probable sleep-related leg cramps (24.1%), excessive daytime sleepiness (22.6%), probable restless legs syndrome (20.7%), and probable REM sleep behavior disorder (18.5%) (Rongve, 2010).

These changes in sleep architecture result in excessive daytime sleepiness, nighttime wandering, confusion, and agitation (sundowning). Disturbed sleep is one of the most common reasons why caregivers are no longer able to care for a patient, resulting in institutionalization. Therefore, addressing the issues related to sleep disturbances in patients with dementia is especially important (Ancoli, 1997).

In part, this may be secondary to the irreversible damage to the brain in areas responsible for regulating sleep, caused by illnesses such as DAT, Parkinson's disease, multi-infarct dementia, and Lewy Body Dementia.

Since it may be difficult for the patient with dementia to describe their sleep disturbance, caregivers can be a valuable source of information. The sleep disorders commonly found in elderly patients also need to be considered in patients with dementia (discomfort secondary to medical illness, the medications used to treat illness, and changes in circadian rhythms). Psychiatric illness, particularly depression, must also be considered. Primary sleep disorders, such as sleep-disordered breathing (SDB), restless legs syndrome (RLS), or periodic limb movements in sleep (PLMS) need to be ruled out or, if present, treated (Ancoli, 2005).

#### 1.3.2.2 Dementia and Sleep Apnea

As mentioned above, patients with dementia often have sleep apnea. One study confirmed that in patients with dementia, those with more severe sleep apnea had more severe dementia than those

with mild-to-moderate sleep apnea, and those with severe dementia had more severe sleep apnea than those with mild-to-moderate dementia (Sforza, 2010).

The correlation between dementia and Sleep Apnea was significant at  $r = 0.37$ . Although it is unlikely that sleep apnea causes dementia, the hypoxia and daytime sleepiness associated with sleep apnea may exacerbate the symptoms of dementia. Approximately 90% of persons with moderate-to-severe DAT have at least five respiratory events of apnea per hour of sleep, 63% have at least 15 respiratory events per hour of sleep, and one-half have at least 20 events per hour of sleep.

As stated before the alterations in human sleep-wake cycles can be part of ageing or they can be also common problems related to dementia. The evaluation through clinical scales can be useful but they rely on the observer's liability, therefore more objective measurements are needed. Actigraphy is an objective and non invasive method to estimate disturbances in human sleep-wake rhythms. Wearable devices like the actiwatch can record activity over a 24h period.

One of the methods assumes that the rest activity pattern has a periodicity through a 24 Hour period. And two distinct periods are evident: a sleep and a wakefulness period. In general the pattern of activity is personal and therefore several days are needed to register in order to identify it. Then deviations from this personal pattern can give information of probable alterations.

## **1.4 ACTIGRAPHY Concept and definition**

Activity can be measured in different ways, we have observational/clinical scales that are well known in geriatrics but they do require some participation from the patient. That is why the use of innovative and non invasive technologies has been a good solution (Brown, 1990).

### **1.4.1 Actigraphy**

Actigraphy is the term given to the technologies applied to measure activity by giving some graphs of the movement as result. It is a relatively non invasive method of monitoring human rest/activity cycles.

Activity actigraphs is the device that registers activity and they are worn and used similar to a pedometer: around the waist, near the hip. They are useful for determining the amount of activity and possibly the number of calories burned by the wearer. They are worn for a number of days. A small actigraph unit also called an actimetric sensor can be more suitable and is also worn by a

patient to measure gross motor activity. Motor activity often under test is that of the wrist, measured by an actigraph in a wrist-watch-like package. The unit continually records the movements it undergoes. The data is later sent to a computer where it can be analysed.

#### 1.4.2 Activity signal acquisition and processing

For example acti-watch systems consists of three main components: a wrist unit, a base station and alarm receiving and routing software. The wrist unit is a wrist-worn alarming device with a manual alarm button and in addition to this; it has a build- in sensors for activity and usage monitoring. The activity signal, which is constructed from the measured force changes at the unit's movement sensor, is continuously wirelessly transmitted on average once per minute, depending on the user's activity level. The activity data is stored by the system allowing online activity monitoring whenever the wrist unit is worn and the user is within the system range (ca. 60m in open space, inside buildings the range covers typical apartment with a simple base station). (<http://www.cephalon.dk/Actiwatch.htm>).

For alarming purposes the unit has a manual alarm with adaptive automatic features, which helps to call for help if the wearer is not capable of doing so. E.g. Because of loss of consciousness resulting in "immobility" detected by the device (Rowe, 2008).

Having explain the function of wrist actigraphy it is easy to understand that the signals can be very sensitive and person dependent. It can be an excellent way to distinguish total daily activity over longer periods.

Actigraphy has been mainly been used for the study of activity patterns and differences related to the sleep/awake rythm. This is based on the principle that there is reduced movement during sleep and increased movement during wake. Since its development in the early 1970's, actigraphs have become lighter, more durable, water resistant, and have included features such as event markers and ambient light sensors. A modern actigraph uses accelerometers to detect wrist (alternatively ankle and trunk) movement, which is sampled several times a second. These data are stored within the actigraph for up to several weeks. The length of time the actigraph is able to record data is typically dependent on the actigraph's epoch length (i.e., the period of time that the actigraphy data is averaged), which is usually 30 seconds or 1 minute.

Actigraph units vary widely in size and features and can be expanded to include additional measurements. However, there are a number of limiting factors:

- \* Fastest sample rate: 1 minute intervals provide adequate detail to measure sleep, but could be too slow for measuring other parameters.
- \* Amount of memory: Together with sample rate, the amount of memory determines how long measurements can be taken.
- \* Battery usage: Some actigraphs have a short battery life.
- \* Weight: the heavier the actigraph, the more disruptive its use.
- \* Water resistance: for proper measurements it is often desirable that the actigraph be worn in the shower, bathtub, or even while swimming/diving.

For some uses, the following are examples of additional features:

- \* Watch functionality: making the device more attractive to the user.
- \* User input: most actigraphs now include a button so the user can indicate a specific event that occurs, for example lights out at bedtime.
- \* Subjective user input: for example a query function to allow surveys at specific times.
- \* Sensors which monitor: temperature, ambient light, sound levels, parkinsonian tremor, skin resistance or a full EEG data stream

Some modern alarm clocks use an actigraph to identify (NREM sleep|periods of lighter sleep), when the sleeper should wake more easily. An application for Apple's iPhone, Sleep Cycle alarm clock, generates graphs of body movement during sleep and has a similar alarm clock function. (<http://thenextweb.com/2010/01/04/closest-sleeping>).

The individual under study is advised to wear the actigraph continuously for a given period of time (usually a minimum of 1 week) but depending on what we are searching this time period can be shorter. In addition, a sleep diary is frequently given to the individual to complete during the time period. This latter information is often used to establish the lights off and lights on time for each 24-hour period. At the end of this period, the actigraph is returned to the clinician's office for analysis. The actigraph is then typically attached to a "reader", a device connected to a computer that allows downloading of the data from the actigraph's memory storage to the computer's hard drive. A computer program enables analysis of these data. At a minimum, a typical program displays and prints a histogram, which shows the individual's activity levels for each epoch over successive 24-hr periods. However, the computer programs usually can estimate sleep and wake based upon user- or

computer algorithm-defined thresholds of activity. Thus, the estimated sleep-wake parameters such as sleep latency, total sleep time, number and frequency of awakenings, sleep efficiency can be derived. But we see the difficulty of such a device that detects so fine movements, that sometimes older persons move much while sleeping, and the device cannot take the difference if the person is awake or asleep. Anyway this type of device has been widely used and studied and therefore the actual guidelines for the study of nocturnal behaviour in older patients have been done for it (Littner, 2002).

In most studies the actigraph has been placed on the non-dominant wrist. Assessments of placement results does not change dramatically, algorithms are relatively insensitive to wrist place- rather, (dominant vs non-dominant) in spite of significant differences in activity levels (Sadeh, 1998).

In the next section an abstract of the extended guidelines done by Sonia Ancoli and her team is given, trying to exemplify the features that seem more interesting and that can be applicable also to environmental actigraphy.

#### 1.4.3 Regulation of the use of actigraphy for the study of sleep disorders

According to a review (Sadeh, 2002), actigraphy is less useful for documenting sleep-wake in persons who have long motionless periods of wakefulness (e.g. insomnia patients) or who have disorders that involve altered motility patterns (e.g. sleep apnea). The authors state the pitfalls of actigraphy testing are: (i) validity has not been established for all scoring algorithms or devices, or for all clinical groups; (ii) actigraphy is not sufficient for diagnosis of sleep disorders in individuals with motor disorders or high motility during sleep; (iii) the use of computer scoring algorithms without controlling for potential artifacts can lead to inaccurate and misleading results. But a new revision was made years later and therefore standards or recommendations levels were proposed.

The term was born when the first actigraphs were used: Since then there have been several innovations. The American Academy of Sleep Medicine (AASM) Levels of Recommendations are defined as standards, guidelines, and options that are cited as follows:

- Standard

This is a generally accepted patient-care strategy, which reflects a high degree of clinical certainty. The term, standard generally implies the use of Level I Evidence, which directly addresses the clinical issue, or overwhelming Level II Evidence.

- Guideline

This is a patient-care strategy, which reflects a moderate degree of clinical Certainty. The term guideline implies the use of Level II Evidence or a consensus of Level III Evidence.

- Option

This is a patient-care strategy, which reflects uncertain clinical use. The term option implies either inconclusive or conflicting evidence or conflicting expert opinion.

#### 1.4.3.1 Major recommendations

The following are recommendations of the American Academy of Sleep Medicine.

Recommendations are given as standards, guidelines and options, as defined below.

- Actigraphy is reliable and valid for detecting sleep in normal, healthy adult populations. (Standard) 2. Actigraphy is not indicated for the routine diagnosis, assessment of severity, or management of any of the sleep disorders. However, it may be useful in the assessment of specific aspects of the following disorders:

(a) Insomnia: assessment of sleep variability, measurement of treatment effects, and detection of sleep phase alterations in insomnia secondary to circadian rhythm disturbance.

(b) Restless legs syndrome/periodic limb movement disorder -- assessment of treatment effects. (Guideline)

- Actigraphy may be a useful adjunct to a detailed history, examination, and subjective sleep diary for the diagnosis and treatment of insomnia, circadian rhythm disorders, and excessive sleepiness under certain conditions:

(a) When demonstration of multiday rest-activity patterns is necessary to diagnose, document severity and guide the proper treatment.

(b) When more objective information regarding the day-to-day timing, amount or patterns of a patient's sleep is necessary for optimal clinical decision-making.

(c) When the severity of a sleep disturbance reported by the patient or caretaker seems inconsistent with clinical impressions or laboratory findings.

(d) To clarify the effects of, and (under some instances) compliance with, pharmacologic, behavioural, phototherapeutic or chronotherapeutic treatment (Ruths, 2004).

(e) In symptomatic patients for whom an accurate history cannot be obtained and in whom polysomnographic study has already been conducted, or is considered unlikely to be of much diagnostic benefit, or is not yet clearly indicated (because of the absence of accurate historical data) or is not immediately available. (Option)

4. The use of actigraphy may be useful in assessing daytime sleepiness in situations where a more standard technique, such as the multiple sleep latency test, is not practical. (Option)

5. Superiority of actigraphy placement on different parts of the body is not currently established. (Guideline)

6. Actigraphy is an effective means of demonstrating multiday human rest activity patterns and may be used to estimate sleep-wake patterns in clinical situations where a sleep log, observations, or other methods cannot provide similar information. However, concomitant completion of a sleep log during the period of actigraphy use provides important supplemental data for the purpose of artefact rejection and for marking bedtime and lights on, which in turn, allows the accurate determination of sleep parameters by actigraphy. (Option)

7. Actigraphy may be useful in characterizing and monitoring circadian rhythm patterns or disturbances in the following special populations: (a) the elderly and nursing home patients with and without dementia (Nagels, 2006).

8. **Actigraphy appears useful as an outcome measure in:** (a) interventional trials in patients with sleep disorders; (b) outcome studies of healthy adults; (c) patients with certain medical and psychiatric conditions; and (d) children and **the elderly**. (Option)

9. Actigraphy may be useful in determining the rest-activity pattern during portable sleep apnea testing.

10. Actigraphic studies should be conducted for a minimum of three consecutive 24-hour periods, but this length of time is highly dependent upon the specific use in a given individual. (Option)

Actigraphy is also appropriate for the assessment of and stability of treatment effects of anything from hypnotic drugs to light treatment to CPAP, particularly if assessments are done before and after the start of treatment. A recent independent review of the actigraphy literature by Sadeh and Acebo reached many of these same conclusions. Some of the research studies failed to find relationships between sleep measures and health-related symptoms. The interpretation of these data is also not clear-cut. Is it that the actigraph is not reliable enough to access the relationship between sleep changes and quality of life measures, or, is it that, in fact, there is no relationship between sleep in that population and quality of life measures? (Acebo, 2006).

#### 1.4.4 Potential benefits

Appropriate use of actigraphy in the evaluation of sleep disorders. Actigraphy may be a useful adjunct to a detailed history, examination, and subjective sleep diary for the diagnosis and treatment of insomnia, circadian-rhythm disorders, and excessive sleepiness in specific clinical scenarios. In hospitalised patients or institutionalised ones, where staff reports the overnight behaviour, but as we will see in our case report, the problem can be that sometimes the reports cannot be very reliable, since staff "gets used "to the nocturnal rhythm or pattern of activity of a patient and specially in long term units they may ignore some changes in activity.

#### 1.4.5 Levels of Evidence for Actigraphy

##### Level 1 (Grade A Recommendation)

Blind, prospective comparison of results obtained by actigraphy to those obtained by a reference standard on an appropriate spectrum of subjects and number of patients.

##### Level 2 (Grade B Recommendation)

Blind, prospective comparison of results obtained by actigraphy to those obtained by a reference standard on a limited spectrum of subjects or number of patients. 4 of 12.

##### Level 3 (Grade C Recommendation)

Comparison of results obtained by actigraphy to those obtained by a reference standard, but not blind, not prospective or otherwise methodologically limited.

##### Level 4 (Grade C Recommendation)

a - Adequate comparison of results obtained by actigraphy to those obtained by a non-standard reference; or

b - Actigraphy not compared to any reference, but actigraph results demonstrated ability to detect significant difference between groups or conditions in well designed trial.

##### Level 5 (Grade D Recommendation)

Actigraphy not adequately compared to any reference, and either

a - Actigraph not used in a well-designed trial, or

b - Actigraph used in such a trial but did not demonstrate ability to detect significant difference between groups or conditions.

\*Reference standards for actigraphic evaluation of sleep and circadian rhythms may include, as appropriate, polysomnography, oximetry, melatonin rhythms, core body temperature rhythms, and/or other generally accepted "gold standards," applied in an acceptable manner. Non-standard references include such items as sleep logs, spousal reports, other experimental monitors, etc.

#### 1.4.6 Accelerometry

Another way of studying movement and more specifically posture and movement disorders is accelerometry. Individuals with movement disorders including essential tremor and Parkinson's disease (PD) often exhibit tremor, bradykinesia and dyskinesias, which can change rapidly and affect quality of life. Available methods include accelerometry, spirometry, volumetry, handwriting assessment, handicap/disability scales, as well as handicap/disability questionnaires. Accelerometry was first suggested in the 1970s, but has only been refined during the past 2 decades. Direct measurement by accelerometry has seen the introduction of the successful implementation of low power, low cost electronic sensors that have been employed in clinical and home environments for the constant monitoring of patients (and their controls). The qualitative and quantitative data provided by these sensors enable engineers, clinicians and physicians to better design strategies of assessment and follow up (Godfrey, 2008).

A wide used device is the Kinesia software, this device is worn on the wrist and finger of the patient and can be used to monitor upper extremity movement disorder symptoms and their fluctuations. Motion and electromyography information from the patient is wirelessly tele-metered to a computer for display and analysis. The Kinesia software also integrates videos, which guide the patient through tasks known to elicit symptoms, similar to instructions given by a physician when evaluating upper extremity motor symptoms. Tasks completed for evaluating tremor are automatically scored on a 0 to 4 scale, which correlated to the Unified Parkinson's Disease Rating Scale (UPDRS).

In a review on accelerometry (Kavanagh, 2008) noted that despite significant progress in the use of accelerometry to evaluate gait patterns, there are several areas of scientific and clinical importance that are yet to be fully explored: the validity of accelerometer-based approaches to motion assessment is scarcely reported. a) There is considerable potential to enhance gait measurement with accelerometers by the addition of rate gyroscopes, magnetometers and electrogoniometers, b) despite the frequently cited benefit of employing accelerometer-based gait analysis to test under "real world" conditions, few studies have actually assessed gait patterns over extended duration, under real-life environmental conditions. The use of accelerometry to assess gait when negotiating

various walking surfaces and other environmental challenges, both indoors and outdoors, may improve the understanding of how subjects behave when performing normal daily activities. Given their portability and relatively straightforward data processing requirements, accelerometers may enable more detailed gait outcome measurement in large-scale clinical trials of patients with balance and mobility impairments.

#### 1.4.7 Why Environmental actigraphy

Having exposed above the different recommendations and guidelines for the use of actigraphy by a wearable sensor, we explain here the special situation that concerns the use of environmental actigraphy by PIRS (Passive Infra Red Sensors). This section is mainly focused on the application of actigraphy for the study of behaviour en more in detail nocturnal behaviour, since this is in our opinion the main concern in the case of managing patients with dementia and BPSD in hospitals or institutions.

Most of the statements mentioned before are related to wearable sensors, and the use of actigraphy to better understand the "sleep/awake" cycle according to different situations or pathologies. Therefore the recommendations are to use as a comparison in a study other validated methods about this cycle like: polysomnography, core temperature, oxymetry. This last ones are dependent variables related to the sleep/awake cycle.

The use of wearable sensors was therefore primarily compared to this type of variables to be another less invasive tool to assess mainly if a person is awake or asleep. As mentioned before the validity of the data can be also influenced by device manipulation by the individual. So a solution is to get information from the subject by analysing his influence on the environment. In our experiment, environmental actigraphy is used to quantify the presence or not of significant activity in a general way as it is explained in chapter 4. PIRS placed in the environment will just give an electric signal every time something who could be a person enters the area identified by the sensor. If we place strategically several sensors, we can cover a room or various rooms and spaces including its entrance, so that a complete "in home" movement pattern can be created. The main inconvenience is that a unique sensor would not be able to differentiate between the presence of one or more persons if they stay static in an area, therefore a system called GARDIEN® was developed and validated. A special algorithm analyses raw data and converts it into useful information. This information can be either very explicit or just give a resume from most important events. For example we can have an automated report that gives a summary of three main activity patterns.

- Agitation in bed

- Displacements in the room
- Activity in the toilet

But the system is also capable of making the difference when several persons are in the room, so that false positive impressions can be avoided. In case of doubt the possibility to analyse the specific sensors activated for a time period is useful. For example if for one night during one hour a unusual high activity pattern is identified, we can first see if the localization of that activity in the room. If for example the toilet and one or several room sensors are activated, so this implies that two or more persons are in the room. It is also possible to see if the outdoor sensor was activated just before to confirm that a person enter the room. But all these situations have already been studied and analysed and are now included in the software of the system, so that it is capable of generating an automated short report giving this information. This will be explained in a further chapter.

In general for research purposes the system can also enable some graphics and give detailed information of which sensor did register the activity. This means a graphic can show in which time period a specific sensor was activated. This is important in the case of patients that either wander in the room; that go several times to the toilet or that leave or try to leave the room. Having a localized pattern of the movements is very important to analyse behaviour modalities. And further more if a precise moment of the studied period is interesting, then details on each sensor activity can be taken to better analyse the behaviour of the patient. This feature can be relevant for the follow up of some drug treatments. So the clinical applications of environmental actigraphy can be diverse as it will be explained in chapters 4 to 6. The concept of smart homes is also described, mainly in chapter 3 when we expose the use of a system that measures activity level of the person through the analysis of data registered from the use of electro domestic appliances. But in fact smart homes are nowadays more sophisticated. Then different types of sensors can be adapted to the whole environment and then dialogue between each other to ameliorate the reliability of the data. This is the real future of smart environments; one unique technology is not enough to cover most variables implicated in the dynamic of a person's activity and autonomy. So the need to create a multi modal system is obvious. Once again we want to emphasize that technology boom is a reality and besides actigraphy, other innovative technologies are becoming part of the usual tools in gerontology. The questions would be then: which type of technology is better suited for a patient? Therefore a user's profile and appropriate approach is needed. The coming section gives an overview on this aspect.

## **1.5 Applications of new technologies in the evaluation of autonomy**

It is a fact that coming generations of elderly persons are more used to innovative technologies, but some of their main fears are that either they feel not confident with new technologies because they do not feel targeted as a special group or they fear to be stigmatized with very obvious devices for elderly. For example like using a cane or a panic bottom device around the neck. But before invading potential users or consumers, we need to profit from previous experiences in related fields. It is a key question to know what determines the use of home services, and we have some answers. Stoddard et cols applied a query to 2000 elderly living in the community on the United Kingdom. From the 79% participants answers got, they found that: increasing age, not owning a car and being a widow was associated to a greater use of statutory and private services. Worse physical functioning, health and cognition as well as foot problems and falls were determinants for the use of statutory and private services. Therefore the need to better understand users is determinant in order to better equilibrate purchasers and providers by addressing some modifiable predictors (Stoddart, 2002).

Seeing this phenomenon from a geriatrician point of view we have to deal with a double task. On one hand be aware of the advantages and disadvantages of the new technologies and on the other hand to know exactly the different profiles of groups of elderly that could profit from new technologies.

Therefore the participation of geriatricians and other professionals in gerontology in the development of new technologies is mandatory.

In this section we propose a perspective of targeting different groups of older persons according to different technologies.

#### 1.5.1. A user's profile qualification

To better understand the need of the population targeted, we need to divide it into different groups. Human beings are very similar when they are born, but throughout live humans differentiate and get old in diverse ways. It is not only a matter of chronological age but of functional resources, gender and in other cases of disability.

Health professionals are used to evaluate the level of functionality to decide which type of help the elderly person needs. Basically this is part of the Comprehensive Geriatric Assessment (CGA) done by the clinical team, usually conformed by a physician, a nurse, a physiotherapist and ergo therapist, a social worker and a psychologist. (<http://www.merck.com/mkgr/mmg/sec1/ch4/ch4a.jsp>).

This type of standard evaluation has been adopted in many different countries and the most used or popular assessment tools have been translated and adapted to the culture of each country. An example is the Katz and Lawton scales, previously mentioned (annexes 3 and 4).

But coming back to the application of innovative technologies. Nowadays physicians and other health personnel need to evaluate autonomy and then suggest which technological aid could be of benefit for a person or patient. We propose five different groups that constitute the target populations.

1. Elderly persons in good health without major handicap, 100% autonomous but with the problem of being alone at home and at risk of isolation. This group would be the target population for technical solutions like: internet services that would facilitate community services to keep in contact with their outdoor environment. The goal for this group is to keep the person at the two highest levels of the Maslow Pyramid (self accomplishment and recognition). Also this group is the target for technologies adapted to the car.
2. Elderly persons at home with some degree of functional dependence but cognitively normal. For example persons with motor deficiencies, hemiplegic or paraplegic in wheel chair. This group can benefit from technologies like: mechanical assistance to mobilize themselves so as adapted electrical home devices to their handicap or the touch sensitive screen to access for example remote control of doors, windows and electrical domestic appliances. The level of technological support has to be adapted to the degree of handicap. The goal is to optimize their level of physical autonomy and self esteem. This means keeping them at the fourth level of the Maslow pyramid.
3. Borderline persons between the limits of frailty. Persons that can have a small handicap either cognitively or physically, but who are able to live alone at home. This group can be the target population for different types of e-health systems. The goal is to verify their degree of autonomy to alert in case of problems. Prevention is the keyword. The idea is to preserve the first three levels of the Maslow pyramid.
4. Patients with some cognitive impairment but without any physical handicap and who live at home. This group can benefit from Tele-assistance and help from services like GPS, home alarm systems for smoke, doors, windows, gas, water leaks, etc. The second goal is to evaluate when the risk of being at home is high and the person will need more aid or should be transferred to an adapted facility. This group is also a target population for the car scenario. The idea is to keep the first two levels of the Maslow Pyramid: physiological integrity and safety.

5. Patients with important physical handicap and cognitive impairment. This is the group that could benefit from Tele-monitoring. Starting from an intelligent home that is in contact with the community services that offer also human aid to all kinds of home devices that can be adapted (bed, WC, rolling chair, automatic doors and lights). It is important to note that this group with heavy disabilities needs human contact to be reassured and the idea of technological support is to facilitate also the tasks for the human personnel. The goal is to keep the person with the best possible quality of life within their high level of handicap. It means helping the individual situated at the base of Maslow's pyramid to keep the physiological integrity and, if possible, reach more.

### 1.5.2 Home telecare technologies

Home telecare technologies have been reviewed by several authors (Kinsella, 1998), and fall broadly into three generations.

**First-generation systems** are designed to reduce anxiety among elderly and high-risk patients and reduce their use of primary healthcare services. Typical technologies include personal alarm systems and emergency response telephones that make a voice connection between the patient and the response centre whenever a pendant alarm button is pressed.

**Second-generation systems** can generate alarms without the intervention of the patient, on the suspicion that something may be wrong. These systems can continuously monitor a large number of variables sensitive to changes in functional health status, and generate an alarm when significant changes are observed. With an intelligent decision-support system using robust algorithms, false alarms are unlikely.

These second-generation systems are unobtrusive, do not require direct patient participation and can be integrated with evolving "smart home" technology for home automation, security and environmental control. New developments include sensor arrays worn by the patient and capable of measuring factors such as temperature, respiration, electrocardiogram and skin blood flow. Ambulatory data can be transmitted to a local computer or specialized controller via low cost telemetry before transmission to a central computer. Local intelligence can be used to detect emergencies and long term trends in health status can be identified and acted upon at the response centre.

**Third-generation systems** attempt to deal with issues of loneliness and quality of life of patients by creating a virtual community of clients, caregivers, healthcare providers and other community services, connected via the telephone, interactive television, and the Internet. In our laboratory, we are investigating the integration of third-generation systems with Internet and Web technology, both for communication and for management and control of monitoring services.

Coming back to the introduction we believe that geriatricians and gerontologist have then a main role in the decision of the development of new technologies and furthermore in the decision of who is really going to be beneficial from them. Some authors have proposed even a special consultation to decide about this. We want with this brief report just to highlight that nowadays in a heavy "technologized" society we are obligated to manage this aspect with our patients in an ethical manner so that they will get the better benefit from it.

## 1.6 Ethics, ageing and technologies

Previously the importance of ethics was named in the case of being careful about evoking a diagnosis specially that of dementia, but also in most of our daily acts as medical professionals we are confronted to ethical issues. Starting from the moment we are in front of a person and we follow our query asking about his or her name, where he lives, with whom, what he usually eats, how often he goes to the bathroom or if he sleeps well. And this all without mentioning all the procedures that we call "medical" and that are a real aggression to the persons privacy and intimacy, but we are allowed to do so because there is or must be, a benefit for the person behind that act.

So when it concerns an elderly person, the situation may even be more delicate, then most persons had another educational background and society was different before, so they may be less confident when they are confronted to all this new technological procedures.

But it is a different matter when the person is in a hospital with a highly technological environment, because the person is not alone, also he might be probably sick and feels reassured. Or it can also be the opposite, that a person can feel unsafe and alone in this completely new environment.

So an important role for the medical staff and the whole team is to detect how the person feels and then try to adapt the situation in order to reassure him.

Some studies have shown that elderly can adapt to technologies and that new generations of elderly will be more and more confident to the fast growing technological boom.

But precisely this boom can it be controlled or should it be controlled? In the recent years ethics has become an important and mandatory aspect to treat in all medical issues.

And when it comes to the development of innovative technologies, this means who will regulate this growth? Who will decide how far can we go with technology? Aren't we at risk of replacing humans by machines?

Aren't we at risk of becoming "big brother" like in Orwell's 1984?

It is truth that video surveillance has become part of the daily life in public spaces in many countries, even those less rich like Mexico.

People are so busy "living" that they do not realize how often they are "watched" while shopping , travelling or using a banking machine in daily life. But now with new technologies we risk to install

also video surveillance at home. In fact as security measures many people have already adopted this option in some spaces.

It is truth that if we apply "common sense" having a video or film from an event can be seen as a "gold standard" and even help for legal issues. It can be valuable evidence. Concerning medical applications this is an excellent tool to study complex seizures or parasomnia. Now if we extrapolate the use of video surveillance to the elderly patients, for sure we could foresee some very specific uses.

It is easy to imagine that having a film about an old lady falling in her kitchen, would give us excellent information about the extrinsic and also intrinsic causes of the fall. Did she slip? Did she present syncope? Did she incur in a risky behaviour like climbing on a chair? Was she aggressed?

For sure for us medical staff, this valuable information could save time in trying to find the causes, would save money while targeting diagnostic measures and treatment...BUT what about the privacy and intimacy of the person?

Would we also accept to be filmed constantly? Might this become a daily life attribute like in public spaces?

Therefore new less intrusive solutions have to be implemented; like is the case of environmental actigraphy. It permits to access in an indirect way to very valuable information about the daily activities of a person. Concerning treatment of "sensitive data" there are existing rules and legislations that have as main purpose to protect private intimacy as it will be explain further in more detail.

We are convinced that we NEED new technologies to gain in time and reliability to better prevent, diagnose and treat the older persons.

Some reflexions about new technologies and ethics are presented treated in the next chapter.

## 1.7 Objectives of the studies done

The purpose of describing the main objectives of the totality of the work done through all these years is to facilitate a general discussion (chapter 7) at the end of this manuscript.

### 1.7.1 General objectives

- a) Show the application of different environmental technologies for the surveillance and follow up of patients with cognitive impairment in two different scenarios. At home and in a hospital room.
- b) To expose the ethical constrains that can appear while using innovative technologies and how this can be managed.

### 1.7.2 Particular objectives for the use of environmental actigraphy for subjects living alone

- a) To evaluate the possible applicability of environmental sensors to detect the level of activity of persons living alone at home.
- b) To demonstrate that the level of activity can be a evaluate in subjects at risk of autonomy loss living alone at home.

### 1.7.3 Particular objectives concerning the use of environmental actigraphy through Passive Infra Red Sensors (PIRS) in hospitalized subjects.

- c) To evaluate the usefulness of environmental actigraphy by PIRS to differentiate the level of nocturnal activity in patients with and without cognitive problems
- d) To evaluate the applicability of environmental actigraphy by PIRS for the clinical follow up.
- e) To evaluate the applicability of environmental actigraphy through PIRS to be use as a gold standard to validate a clinical score.

## **RESUME DU CHAPITRE 2**

Dans ce chapitre nous abordons l'importance de prendre en compte l'éthique lors du développement d'une nouvelle technologie. Tout d'abord nous discutons le besoin de réglementer une attitude éthique dans ce développement en suivant les guides proposées par les organismes responsables. Puis nous faisons une analyse plus détaillé de certaines technologies en partant du traitement des données, jusqu' à l'utilisation des robots et d'un environnement intelligent. Dans la dernière partie nous montrons les résultats d'une enquête concernant les questionnements éthiques lors du développement des nouvelles technologies. Deux groupes ont répondu aux mêmes questionnaires, l'un impliqué dans le développement des nouvelles technologies dans le cadre d'un projet européen et l'autre constitué de participants à un espace éthique Alzheimer.

## **CHAPTER 2. AN ETHICAL REFLEXION ABOUT THE USE OF INNOVATIVE TECHNOLOGIES**

### **2.1 Introduction**

One major issue that is mandatory to be discussed in any research project nowadays is ethics. There is not much legal-ethical support “well” defined. For sure there are many instances at political level that have rise the issue, but there is not still a precise chapter regarding the use of innovate technologies for elderly persons. Most supports either explain the potential risks but are not really clear about what to do and who really regulates it. So the need to act has been highlighted one decade ago (Widdershoven, 1998). But it is not so dramatic since there are also some ongoing projects that will give some concrete answers in the future years. In this chapter some of the technologies that are potentially used with elderly persons and are those that we will work with along one of the projects that is still ongoing for two years.

### **2.2 The need to regulate the technological boom**

Technology in the last ten years has known an explosive development concerning a new market population target, the elderly. Yes the elderly population is not only a threat to the health budget as mentioned at the beginning, no this growing population has been well identified as a “market target”. Pharmaceutical industry has therefore engage in producing adapted dose treatments for this population. Therefore strict regulations exist regarding the production, experiment and commercialisation of medications (UNESCO,2004). For example in France the Huriet law is very clear. But unfortunately this is not the case for the regulation of the experimentation, the development, use and ethical constrains due to innovative technology (Fagot-Largot, 2000).

## **2.3 Who regulates technology development**

A growing life expectancy carries many challenges with it. One goal from the *active ageing* programme in WHO is to encourage successful aging in all societies. The word "active" refers to continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labour force. Older people who retire from work, ill or live with disabilities can remain active contributors to their families, peers, communities and nations. Active ageing aims to extend healthy life expectancy and quality of life for all people as they age. ([http://www.who.int/ageing/active\\_ageing/en/](http://www.who.int/ageing/active_ageing/en/)).

To achieve this task another question is raised: how can we help older people stay autonomous and at home in the best conditions and as long as possible? The answer has many perspectives and one proposition relies in assistive technology. But society can be surprised and fear the replacement from human support by assistive devices. Therefore technology and ethics can often be seen as excluding each other. With the rapid speed at which technology grows, the average person not used to this development can feel not confident specially the elderly population who is less used to innovative technologies. On one hand this phenomenon can be due to the fear of being confronted with the unknown and on the other hand the feeling of being observed or watched. The main ethical and universal question is probably the principle of avoiding to hurt and to provide benefit in all sense. To do so many experts in different fields have argued from many points of view but we still do not have all answers.

So this issue has been treated from the top International Organisations to the simple lay persons in order to better rule or organise the research and use of innovative technology. The main risk for research in this field is to go too far and substitute instead of helping and to survey instead of assisting. Especially regarding the geriatric population, researches have to avoid to eliminate human contact or to do too much to "help" risking to become deleterious (<http://www.unesco.org/shs/ethics/geobs>).

Older adults see the use of a very diverse range of technology and accompanying services as a solution to facilitate independent living and compensate for decline in vitality. Moreover, as commented by J van Hoof, there is a push on older people by the technology driven society to incorporate technology, such as internet banking or buying into daily life. Trying to find the right dosage of aid for a person is a hard task, because it needs to be Taylor-made and with the agreement of the person. Then this has to be done by a multidisciplinary team like every other

decision in the field of gerontology (Van Hof, 2007). Another important factor is the evaluation of the user's satisfaction, an imperative topic according to (Guillen, 2002).

To introduce ethics in the frame of this project, we can examine first the threats and vulnerabilities to ethics in the application.

According to the international guidelines and the specific legislations that can regulate and help to the appropriate development of research with human beings within the European Union and in each country participating.

According to Rialle there is an enormous push of technologies, some of them planned to bring hospital to the home of patients in some cases with precise pathologies, mainly Alzheimer, in order to avoid transfers to hospital. In other cases Information Technologies on Communication (ITC) are more and more common for daily life tasks like: cellular phones, internet, electro domestic appliances with remote controls or there are also sensors capable of sending physiologic data at distance to allow a patient to be surveyed and access immediate help in urgent cases as is also the case for older people who benefit from fall detectors. In this last special case which is a great health problem even nowadays with the help of technologies it is not always a resolved problem (Rialle,2007).

So there is a place to promote telemedicine and to enlarge the net of health services especially in rural areas. On one hand the increasing population ageing and on the other hand the high health expenses that are related to this phenomenon. One goal from this promotion of the use of technologies following Rialle's ethical point of view, is trying to offer the benefits from these innovations to the more fragile ones really needing them but under a rigorous control following an ethical and legal framework.

It has been proved that the development of technology is itself a social practice which involves or should involve ethical values and therefore can be questioned from an ethical perspective.

One thing that should never be forgotten is that acceptance of science and technology depends upon various social groups. And the users are the main target but also the deciders. Today we know that technology and ethics do need it each other. The fate of a technological device is in the hands of the users. So the development of a technology is the result of negotiations between social groups, each interpreting the device in a specific way. So there is a special interest to keep all aspects focus in the final use and the end user. Therefore, nowadays much of the ethical framework has been done. Many rules and laws exist that permit a better understanding and guide through gerontechnological research.

It is the role from actors in research and development to promote and facilitate the implementation of technologies at home, with the goal of helping, assisting at the medical follow up and of autonomy from older people, while preserving all ethical aspects that will be discussed.

## **2.4 The ethical evaluation of technologies**

Within the frame of a technological innovation in health care, people will spent their time negotiating about the definition of a situation. The engineer will propose a device, the physician will rather find out how it would be used to make his work more efficient, the patient/user will be more at the mercy of the others and will participate by testing the device. The physician will try to understand the patient's wishes but will probably not take all the values from it. So the outcome of such a process of dialogue and negotiating has given the background of expertises to further research from an ethical point of view.

In recent years attention is being directed towards technology that learns from and helps to regulate human behaviour (Fisk, 1997). Especially older people can delegate control over certain aspects of their everyday lives to technology while continuing to exert direct control in others (Lindenberger, 2008). The design and evaluation of human engineering technology is much a psychological task as it is a technological feat. In particular, intelligent, adaptive assistive technology needs to be constructed by technological opportunities, psychological knowledge and aging individuals themselves. To be effective it has to learn, adapt to the needs, habits and preferences of individuals, preferably well before major cognitive, sensory and motor impairments have set in. Another important issue is net resource release (marginal resource benefit). The operation of technology usually requires an investment of physical and mental resources. It follows that the use of technology is adaptive only if the operation costs are lower than the payoff associated with other changes in processing when using the technology. For example, if the use of a notepad as a memory aid requires memorization of complex instructions, then the payoff of using the device may be negative, at least initially. So it is important to have a previous evaluation of the actual skills of the user and taking into account that these might diminished over the time, which is the inverse case from children and younger adults or older people without cognitive impairment whose skills might ameliorate thanks to training. Since this is not an easy task, trying to figure how things happen for the others or better said, trying to put ourselves in the shoes of the others; it can be pertinent to comment about the importance of human factors in the development of these technologies .

As George Demiris said, the power of human factors research relies on what the patient or any end user may need or appreciate. Therefore it is mandatory to include patients in the design of systems so that the use of proper methods to assess their needs and expectations can be done and more acceptable user friendly systems can be succeeded (Demiris, 2000). Gerontechnology covers such a big field, and different aspects of the older people's life that we propose to approach the subject according to the type of technology. Gerontechnology is based in large measure on its goal to reduce or prevent individual and social- structural lag in the relationship between people and their environment.

A major role for this is the place of ergonomic but from an ethical point of view. The confidence in technologies is a main worry for users who want to master their actions and interactions between them and the machines and for sure their inter relation with other persons through these technologies. They need to know their role in this interface and be reassured permanently. In this manner ergonomic gain an ethical dimension in this relation between persons and technologies.

One way to make this field more ethically efficient is as it was proposed by Powell Lawton ten years ago, to include "hedonometrics" as a goal. This means methods of assessing the feeling aspects of everyday life, including both positive like fun and enjoyment and also the negative aspects of the behaviours in the instruments utilized in the satisfaction of people's needs (Powel, 1998 ).

## 2.5 Different technologies and their ethical acceptability for the ageing society

### 2.5.1 Data Security and Privacy

Probably in medical practice the most sensitive issue related to ethics is privacy and confidentiality of the data held by the Health Professionals (Ferrer-Roca, 1998 ).

The notion of voluntary participation in research involving human subjects was enunciated for the first time in the Nuremberg Code and then in several international declarations: Declaration of Helsinki (2000), Convention of the Council of Europe on Human Rights and Bio-medicine (1997), UNESCO's Declaration (2005), WHO/ CIOMS (1993). It stipulates that prior to consent, each participant in a research project should be clearly informed of its goals, possible adverse events, and the possibility to refuse to enter or to retract at any time with no consequences.

In Europe this has been regulated by the (EU Directive) for processing personal data and controlling its transfer. This is covered by the directive 95/46/EC that defines data privacy until Oct 2007.

Sensitive personal health Data is recognised in Art.8 (special categories of data) and have the following premises:

C- Confidentiality

I - Integrity

D - availability and disposal

Confidentiality is defined as the property which assures that only authorised users in normal conditions can have access to the system.

Integrity is the quality which insures that information is only modified by its usual in normal circumstances.

Disposal or availability is the ability of an information system to be used by authorised users in normal conditions of access. Violation of these principles poses serious doubts on the data integrity.

Standards in health Data handling are regulated by the standard body of medical informatics that classify Health Information Systems in terms of Requirements following these points:

- 1) security
- 2) Rectification, Erasure and Blocking
- 3) Third Party disclosures
- 4) User authentication
- 5) Data Origin and consents

Nowadays data protection has been developed and private and public organisations use security systems to protect them. Cryptation of personal information is mandatory and only relevant data for a research study are held in an anonymous way. Few authorized persons might have access to sensitive data.

### 2.5.2 Data collection and processing

Data must be collected for specified, explicit and legitimate purpose.

The controller cannot further process the data in a way incompatible with the initial purpose: this implies that he has to satisfy the conditions for the reuse of personal data, especially for statistical, historical and scientific purposes.

The duties of the controller relating to data storage are:

- Keeping them accurate and up-to-date where necessary,
- Keeping for a limited period of time,
- Respecting rights of data subject: right of information, access rights, right to ask for data to be rectified, the right to object to the processing,
- Taking technical and organisational measures ensuring the data security and confidentiality,
- The legitimacy of the processing is, according to article 7 of the Directive, based on one of the social justifications laid down by laws. The unambiguous consent given by the data subject is one of those justifications.
- Processing of medical data is also subject to even more restrictive conditions. In principle, their processing is prohibited but may be permitted in specific circumstances (art. 8):
- When the data subject has given his/her explicit consent to the processing of those data, excepted when the national law of a member state provides that the prohibition may not be lifted by the data subject's giving his consent.
- When the processing of the data is required for the purposes of preventive medicine, medical diagnosis, provision or ease of treatment, the management of healthcare services, and when those data are processed by a health professional subject to the obligation of professional secrecy and by another person also subject to an equivalent obligation of secrecy.

Lawfulness of the processing is realised through conditions regarding the quality of the data, which are:

- Data must be processed fairly and lawfully,
- Data must be collected for specified, explicit, and legitimate purposes,
- Personal data must be adequate, and relevant and cannot be excessive,
- Personal data must be accurate, and when necessary, kept up-to-date,
- Personal data should be stored for a limited period of time.

Communication of data to third parties also knows a legal framework. Medical data should not be communicated unless the following conditions are fulfilled:

- The medical data are relevant for the purpose of the communication, AND
- The recipient of the communication is subject to confidentiality rules equivalent to those incumbent to healthcare professionals, AND
- EITHER the communication is authorised by the law and is made for one of these reasons:
  - Public health reasons,
  - Prevention of a real danger or suppression of a specific criminal offence,
  - Another important public interest,
  - Protection of the rights and freedoms of others,
  - Protection of the data subject or a genetic relative,
  - Safeguarding the vital interest of the data subject or a third person,
  - Fulfilment of a specific contractual obligations,
  - Establishing, exercising or defending a legal claim,
- OR the data subject has given his/ her explicit consent,

OR the data subject has not explicitly objected to any non-mandatory communication, if the data collected in a freely chosen preventive, diagnostic or therapeutic context, and if the purpose of the communication, in particular the provision of care to the patient, or the management of a medical service operating in the interest of the patient, is not incompatible with the purpose of the initial processing.

### 2.5.2 Telemedicine

This service or field of medicine has now a well known acceptance and reputation. The bases of telemedicine are founded on the international consultation carried out by the WHO in 1997. In this report a working definition was given for " health telematics"; composite term for health related activities, services and systems carried out over a distance by means of information and communication technologies, for the purpose of global health promotion, disease control and health care, as well as education, management and research for health.(European Union Directive) But also the American Telemedicine Association has proposed some guidelines (<http://www.americantelemed.org/icot/hometelehealthguidelines>).

Ferrer-Roca in 1998, in his handbook explained that one main reason for slow acceptance of telemedicine was the limited number of rigorous trials and gives the minimum scientific requirements in a telemedicine trial:

- well designed experiment
- appropriate control cases
- sufficient data for analysis to obtain generalized conclusions
- serious and appropriate statistical evaluation (Ferrer-Roca(b), 1998)

In this decade telemedicine has evolved and its regulation has also changed.

The deontological medical code accepts that:

1. the computerised systems in Medical Informatics do not affect the patient privacy rights
2. also that all computerised data obtained from the patient clinical history should be under the doctor responsibility
3. and finally that personal medical data should never be connected to non-medical networks.

It may be interesting to propose that for example once that the system detects a danger for the subject in any of her activities of daily living or just the need for help, then the assistant, either a machine or the personal assistant could visualize what is happening. In this way the assistant could help either by communicating with the subject or guiding him or just help to better perform an activity. The ethical question would be, how far should we go with the assistance and how far is it allowed to survey in a person's private environment?

So the assistant, who can be a member of the family or a chosen person, could be authorized to interfere in the person's environment under some conditions predetermined and according to the existing ethical laws.

For example already in 1998, Couturier here in Grenoble experience with orthopaedic teleconsultations showing good acceptance from all arts, the teleconsultant specialist, the assistant who was the physician and the patient. This type of interventions can avoid tiring, time consuming and costly transfers from patients (Couturier, 1998).

This intervention would have as main purpose to help the person stay as long as possible at home under a safe condition. In this way the person would preserve his social life in his environment which is a basic ethical point. In other words, while protecting the life of someone in his

environment as long as possible, we are directly protecting his autonomy. And we can even help to ameliorate by using technical aids at different levels: cognitive, physically and just facilitating daily life (Kinsella, 1998, Kuprinsky, 2008).

Tele-health can also be provided in Institutions for older people, like nursing homes and hospice. The ethical issues that can be underlined are well describe by (Demiris, 2001).

They are:

- privacy information,
- informed consent,
- equity of access,
- autonomy vs. dependence,
- lack of human touch,
- medicalization of the home environment and
- usability

All aspects should be treated by each user in a setting and interact (patient, care giver, nurse).

In 1997 the World Health Association (WHA) underlined some ethical aspects of telemedicine. First of all we cannot forget that many ethical aspects already belong to each physician in his normal performance, so acting through telemedicine, will keep this ethical point. The development of technologies in communication opens new modalities of health care. These are justifying by the speed of accessing patients in special situations. About the patient- physician relationship, the WHA underlines that this situation has to be based on a personal meeting and a perfect knowledge of the patient's medical history. The use of telemedicine should be reserved for cases when the health personnel cannot be available for a reasonable delay. In the best case telemedicine should be started only after having had at least one traditional face to face medical consultation (Liashenko, 1997).

Another issue that was mentioned is the assurance of data protection, privacy and professional secret and this can be assured through data cryptation.

Concerning the responsibilities for the health professionals, the accomplishment of a medical follow up should be guarantee and the professional has to assure that the patient and his caregivers have understood the use of the technology or devices to be used.

The family physician will still keep his role as main actor in the follow up of the patient.

Another important issue is to certify that the quality of a medical act done during a telemedicine process is guaranteed, this implies the good use of the technology and the quality of image and sound transmission. The physician has to decide when a personal contact is necessary.

The use of telemedicine in emergencies has also been discussed, the advices and proposals given will also depend of the skills from the patient and the persons in his entourage. So the WHA invites the different countries to better legalize the framework in which telemedicine has to be developed and work.

For the French case there is recognized will to do things correctly and last November an official report about the role and legislation of telemedicine in France has been published by the National Ministry of Health (NMH). Just to highlight some important aspects (Simon, 2008).

To clarify the medical responsibilities in telemedicine and not e health, this can be covered through three different acts:

- Tele consultation: this is a medical act that requires the presence from a patient and a dialogue is pursuit between them.
- Tele expertise: is usually the act between two or more professionals in order to have a better opinion and it is held without the patient.
- Tele surveillance: is a medical act starting from data collected from a tele transmission. This can be biological, clinical, and radiological or any other data gathered by the patient or by a health care giver. The medical professional can then analyse the data and decide who has to take charge of the follow up, himself or delegate the responsibility to other health care professional, but this has to be protocolize (Helsinki Declaration).

Tele assistance can also be the help given from a medical physician to a colleague for a medical procedure or consultation, like in the case of emergencies in accidents. Physical Closeness is conceived to be an embodiment of caring in nursing. Tele-health systems introduce a reality where nursing care no longer necessarily occurs in any certain physical space. What (Liaschenko, 1997) calls "the arena of direct care" can include cases where the patient and the nurse are separated by geographic distance.

To finalize according to the roundtable discussion held by experts from the American Telemedicine Association (ATA) in December 2008 about human factors and telemedicine we can resume.

Telemedicine strategies have been applied in different medical disciplines and geriatric expertise is not universally available, even in industrialised countries. Brignelli et cols showed that there were 26 papers out of 78 that regarded elderly patients. They concluded that telemedicine has the capacity to allow remote consultation using the comprehensive geriatric assessment, since we cannot rely on the recruitment of local geriatricians. Cost effectiveness can be achieved through the use of existing and wide spread technologies like, internet (Brignelli, 2007).

To be part of a telemedicine system a basic ingredient is empathy, specially in the case of older people who are vulnerable. **Empathy** is a skill that now can be developed and learned, it is also part of the training for people involved in telemedicine. So it can be possible to keep a human warmth through tele consultation and tele assistance in tele gerontology.

### 2.5.3 Internet

Internet includes all other technologies that are related to him (satellites, mobile phones, computers, WIFI, etc) and it has become omni present in human life. Its influence, capacities and incidence on the life of humans cannot be measured.

Information and Communication Technologies (ICTs) form a substantial part of all technology around us and are omnipresent in the living environment; ICT s collect and disperse a high volume of data from all kinds, personal and public and the systems are becoming intelligent and autonomous. Governments and professionals delivering services use internet worked technologies to assist and monitor citizens and clients. Privacy and ethical implications of networked, ubiquitous technologies in and around the home environment are of increasing concern and possible Orwell's big brother scenarios might be arriving.

Concerning the unauthorised access to the system, identity theft is a risk in this environment: that's why a secure system for the broadcast of information is required and also that critical data entering or leaving the system should be secured. The electronic system should ensure that filtering of incoming data meets the consumer's requirements. It should ensure that the critical outgoing data is secure and adequately encrypted.

Concerning e-health services provided over internet, the question of liability shall be raised.

Liability is at stake when a causal link between the harm suffered from and a defective product is found. That means that if an error exists in decision-support software, the doctor who relied on the software would have a claim based on Council Directive 85/374/EEC (EU Product Liability Directive).

Currently, there is no general harmonisation between countries of liability rules for services in which no defect can be found in a device.

In the context of Web-based disease management, access to and ownership of the data have to be addressed. In many Web-based applications in home care, patients record monitoring data and transmit them daily to a Web server owned and maintained by a private third party that allows healthcare providers to log in and access their patients' data. Such an application calls for discussion and definition of the issue of data ownership and patients' access rights to parts or all of their records. The implications are not only possible threats to data privacy but also ethical debates about the restructuring of the care delivery process and introduction of new key players (Demiris, 2001).

Moreover, to manage rights and duties arising from an e-Health service provided via the internet, some obligations shall be followed by the provider:

- Informing the user of his identity, address and VAT number if applicable,
- If the service is provided by a doctor or other profession subject to the rules of professional registration, provision of the full registration details applicable in the country of registration is compulsory.

#### 2.5.4 e-HEALTH

E-health is related to all applications about health issues that everyone can find online. Therefore in the case of France, in 2007 a new legislation was established in order to verify the legitimacy of the content in these websites. Since then websites on e-health have to be approved by a Suisse NGO (Non Governmental Organisation) "health on Net". The Health On the Net Foundation (HON) promotes and guides the deployment of useful and reliable online health information, and its appropriate and efficient use. Created in 1995, HON is a non-profit, non-governmental organization, accredited to the Economic and Social Council of the United Nations. For twelve years, HON has focused on the essential question of the provision of health information to citizens, information that respects ethical standards ([http://www.hon.ch/index\\_f.html](http://www.hon.ch/index_f.html)).

This intervention is a key to ensure a good quality of the information given about health issues, which is a major ethical constraint that was not regulated before. The problem exists when websites are being created at a high speed and that users cannot identify which web pages are certified or not.

In order to make optimal use of e-Health tools, there is a need for a definition of the purpose finality concept that would provide an adequate balance between protection of the interests of the individuals on the one hand and public health management and disease prevention on the other shall be reached (Hwang, 2008).

A major constraint in e-health can be the quality and acceptance of the data transmitted through all the technology used. On one hand the aspect concerning the privacy, but this has been already commented in the data protection chapter, but on the other hand the performance of the devices could be a question of fear for the end users, specially the patients. How can we convince our patients that the electronic device they are wearing or that is in their room will not fail? Are we sure that we can rely on our technologies to follow up our patients at distance? Can we take important decision through these devices?

Fortunately, most of these questions have been answered through strict research protocols and technologies used in e-health services have been approved.

E-health based on mobile wireless networks is called mobile e-health. The International Telecommunication Union (ITU-D) has promoted mobile e-health for example in case of emergency. An example is the Tsunami Cooperative management, which are the process notations and tools used in e health care that involved the collaboration of multiple human roles assisted by networked

information systems. So according to the saying you can manage something that you can measure, an important task is to define a *measure of cooperation*. E-health needs a platform of services that are well coordinated and safe (Pradeep, 2008).

Another point is the concept of awareness level. This is based on factors like location and actions of the users involved. An important issue here is related to other subjects treated before like: what information to provide, how to provide the information, how to facilitate interruptions and how to allocate control of the information.

According to Rialle, there is an important symbolism from patient's home that should be conserved and protected. The home of patients is a particular sensible place, since it differs from public settings in that it is «our place, a place for us» Therefore it is not contemplated to invest in patient's homes without a legal accord and over all without the authorization from the patient (Rialle, 1990 and 2007).

So in general, e-health is accessible to everybody through the net and the most important challenge for authorities is to supervise and regulate the quality and credibility of the information posted. The risk of misusing information from some fraudulent websites will always be there and a great responsibility relies on the consumers. As commented before in some countries web pages dealing with medical information need to be certified by an authorized agency designed by the authorities.

In fact Baruch did make a complete analysis about ethics and the use of electronic surveillance, specially concerning patients in nursing homes (Baruch, 2006).

### 2.5.5 Assistive Devices

Assistive devices are essential for many older people, and mainly for disabled people (older people or not). Among the wide spectrum of assistive devices, the ones of interest for MIDAS are those related with information technologies.

As stated by Trent Dementia Services Development Services, there are 4 principles that go back to the foundations of modern medicine. These are the principles of Non-maleficence, Beneficence, Autonomy and Justice.

- Non-maleficence simply means "does no harm". In other words we need to ask ourselves, "are we in danger of doing more harm than good?" For example, considering whether there is a risk that a piece of equipment may lead to more confusion or distress.
- Beneficence means striving consciously to be "of benefit" to the person. In other words the intention should be to benefit the potential user, for example by enabling access to support or help if they fall or helping them to take their medication.

- Autonomy refers to respecting the person's rights to things like self determination, privacy, freedom, and choice. E.g.; if a sensor mat is used to help monitor fall risk, would it be used just to tell the person not to walk or get up or would the person be offered a companion to walk with safely?
- Justice means treating everyone fairly. For example providing equal access to technology, or taking into account diversity and individual differences.

When discussing whether an assistive system is adequate or not in a specific situation, we can follow the previous principles in order to formulate questions like:

- Does the situation really call for a technological solution?
- Maybe the needs of the user can be met in another more adequate way?
- Do we consider the wishes of the user and taking into account their strengths?

In sum, when it comes to gauging the long-term consequences of intelligent assistive devices, both risks and opportunities need to be kept in mind. On one hand chronic reliance on technological aids may deplete resources through protracted disused skills and abilities, undermine motivation and engender loss of autonomy. On the other hand intelligent and assistive devices may activate latent potential by combining support with challenge, thereby enhancing motivation, social participation, and a sense of autonomy, with positive repercussions (Craen, 2006).

Furthermore, when using Information Technologies (IT), these ethical considerations do intersect with typical ethical aspects of IT per se, such as security or privacy. Once it has been determined that an assistive system is adequate, we can observe that it often requires an active monitoring of the user, so it has to be observed how this could potentially be misused. Because of this, there should be always guaranteed an ethical compromise between the privacy of the user and the gathering of data which is needed by the system in order to be useful. It must be guaranteed the correct usage of such inputs to the system. For this purpose, authentication and data protection policies should be implemented at any time that getting input data involves an intrusion in the privacy of the user.

When a research project is focus in multimodal interfaces and relating them to assistive technologies, it must be guaranteed that such interfaces are really adaptable, in order to reduce discrimination at its most, and thus serve the widest possible range of users.

### 2.5.6 Robots

Ethics guidelines are urgently needed to control the growing use of robots in caring for children and older people, was a statement from. Professor Noel Sharkey, of the Department of Computer Science at the University of Sheffield, published late in 2008 in the journal Science. Sharkey argues that the steady increase in the use of robots in day-to-day life poses unanticipated risks and ethical problems. He says there are also already many "elder-care" robots in wide use, such as the Japanese "My Spoon", which can automatically feed older people, and an electric bathtub robot that can automatically wash and rinse them (<http://www.technovelgy.com/ct/Science-Fiction-News.asp>).

The main question is how can we find the limits? For sure robots can interfere with human contact if their use is abused, but finding the proper use, robots can be the opposite. Robots can help caregivers with difficult or repetitive tasks.

Sharkey also stated: I have no concern whatsoever about robots taking control. They are dumb machines with computers and sensors and do not think for themselves despite what science fiction tells us, he says:"It is the application of robots by people that concerns me and not the robots themselves."

According to the United Nations Economic Commission for Europe's World Robotics Survey, in 2002 the number of domestic and service robots more than tripled, nearly outstripping their industrial counterparts. So what exactly is being done to protect us from these mechanical menaces? ([http://www.unece.org/press/pr2004/04robots\\_index.htm](http://www.unece.org/press/pr2004/04robots_index.htm)).

The newly emerging field of machine ethics (Anderson and Anderson, 2006) is concerned with adding an ethical dimension to machines. Unlike computer ethics which has traditionally focused on ethical issues surrounding humans' use of machines; machine ethics is concerned with ensuring that the behaviour of machines toward human users and perhaps other machines as well, is ethically acceptable.

There is an urgent need for guidelines for a better use with an ethical perspective of robots. The high speed at which robots are developed and commercialised needs to be revised.

Another issue has been raised in the field of robotics. The great fear as exposed in some science fiction movies, when the machine becomes autonomous and destroys his creator is a risk?

In the case of robots to assist daily living that have been tested, we can say that some can have some therapeutic goals like helping people walk, other have been proposed to help with domestic

tasks that can be fastidious or to give an idea of the level of activity, as commented before in the case of intelligent environments.

Home robots offer a new way to communicate and interact with patients while they remain in their own homes. It can perform face recognition and help locate people in a room. This fact can be seen as rather intrusive but in case of emergencies could it be justify. For example a robot can help a patient with its medication follow up, which in this case can be safe and well done. Robots would be a major help for patient, and health costs, if we consider that patients with chronic diseases have a low compliance to treatment around 50% (Tackas, 2008).

But another concern or point to discuss is the use of humanoid robots. These type of robots have been inspired from science fiction and the main idea was to help humans by replacing them to do the repetitive, fastidious or dangerous tasks.

Their use in gerontechnology is well known. These robots can be presented as a solution to an accompany person or like a substitution from some health personnel under two hypothesis:

One that gives a solution to the lack of humans to help older people in our actual society, these humanoid robots can always be there, in good mood to help and assist the older persons, without getting tired or stressed.

The second hypothesis, probably more acceptable is that we do not have enough health care workers in our institutions to take care of older people, so these robots are a good solution to replace the missing personnel.

But the ethical issue is that if this is going to be the future of our society? (Minsky, 1994).

### 2.5.7 Intelligent Environments

Different authors have published about the benefits of an intelligent house or an intelligent environment. This electrical revolution continues and today many houses are equipped with various technologies to support household activities to provide comfort, and when needed, to assist with activities of daily living. The computarization of our residences started in the early 1980 not only with personal computers but also to the introduction of domotics or home automation systems.

In the near future homes are expected to serve as an integrated part of an ambient intelligence environment with situated and distributed services that will learn from individual users. Users and environment will interact and react to changes according to the user conditions and needs (Berlo, 2005).

Under these circumstances no obvious disadvantage can be detected if the system works well.

Intelligent environments have been used for research purposes with older people. An example is the use of Passive Infra Red Sensors (PIRS) for windows and doors to follow up the displacements of a person in the house. PIRS can also quantify activity, which is a good marker of the individual's autonomy (Banerjee, 2003). Furthermore, to evaluate the level of autonomy a multimodality of sensors or devices can dialogue in an environment to have a broad spectrum of the person's performance from different points of view. Intelligent environments can be more sophisticated and even include medical technology. Activity sensors enable to track people movements from room to room. They are either infrared-based devices or magnetic contact switches. Actimetry sensors are used to detect fall, vibration. The body actimetry sensor is a wearable sensor which has been developed to predict the situation of a person. It is composed of three sensors: vertical acceleration, body orientation and mechanical vibration of the body surface. The combination of data given by activity sensors and actimetry sensors is used to determine the position of the person, for instance sleeping, lying after a fall, walking. Physiology sensors collect physiological parameters such as blood pressure or weight. Environment sensors detect smoke, measure home temperature and hygrometry (Pigot, 2002, Susuky, 2006)).

The package automation and control of the home environment, existing for over a decade, supports the control of the physical indoor environment, i.e., temperature, ventilation and lighting, as well as home security devices or automatic kitchen equipment (Tamura, 1998).

Here again we have to ask ourselves how far can we go to trace a person's autonomy through information about her private life. We can follow the displacements of an individual, we can know if the person is watching TV or using the coffee machine, if the person is using the WC very often etc, etc (Corte-Franco, 2008). But in daily life medical doctors use to ask questions about the private life of the patient in order to have a better understanding of the global problem from the person, therefore we believe that once again that information gathered from an intelligent environment should be restricted and managed according to the data protection laws existing. In this way we can assure a respect from the privacy of the person.

Good ethical practice involves asking questions that concern dilemmas that can arise when considering the appropriateness of technology for a certain person or groups of persons. Ethics and privacy related issues of modern ICTs are closely linked to limited awareness of the presence of these technologies due to minimization. Here we can have two aspects, when a person after life threatening problem needs to "bring the hospital at home", this can be rather shocking for the ambiance and other living at the same place, since most systems are very intrusive. But usually this is not a problem, since the person prefers to be at his home rather than a long period hospitalised

or in a setting. But when the systems are unobtrusive the only problem would be the implications of data collection and transmission mentioned already.

### 2.5.8 Global Positioning Systems (GPS)

The use of Global Positioning System has been widely commercialized. It has proved to be a useful device in most cases, because usually it is being mainly used for personal purposes. It can also be use for special legal aspects like trying to verify the position from ex convicts or trying to localize subjects or places with military or legal objectives. Tracking technology has been of interest for years, since movement trajectories give important information (Mulder, 1994). But the main idea is to use GPS as a tool to help persons in case of problems, hesitation or danger.

In the case of dementia patients, a particularly vulnerable group of older adults who is estimated around 25 million worldwide, then they can meet a special situation to use this technology. To cope with the problems accompanying wandering a potential lethal behavior, track & trace systems can be helpful. Which means not to put an ethical restrain on people. Once again the need to involved the end users in the process is crucial, especially when persons from different perspectives are being involved, the patient and the caregiver or family member (Faucounaud, 2009).

In this special case it can be argued that a slight loss of liberty is acceptable in order to increase safety. At the same time, electronic tagging satisfies an ethical principle and decreases stigma (Rahimini, 2007).

Nowadays there are not official laws to the public to get a device and therefore we believe that we need to be cautious about its use.

- Like with other devices, it's use should be only with the consent from the person who is going to be the target.( see informed consent below)
- In case the person is not able to give her informed consent then the legal proxi has to do it.
- It must be explained that the purpose of its use is for the benefit of the individual to be target
- The information gathered from the device should also follow the rules mentioned above about data protection.
- The data will be used for the strict purpose of the project.

GPS Location Based services use the following scheme: a request is sent through GSM network, GPS device compute in real time its position and send back it through GSM network to a location platform service. The result is the position of a person on a map including his exact address and the date, time, latitude, longitude of the position which can be communicated to emergency services (for instance fireman).

Some applications targeting elderly people provide a dedicated assistance where the person is located. Here we feel a risk of infringement on the freedom. Location Based services in and around the home environment are of increasing concern and can be qualified as a big brother service if no rule is defined.

In France, the CNIL (Commission Nationale de l'Informatique et des Libertés) is a public organisation in charge to restrict the usage of data from private life. It was created by the french rule n° 78-17 in January 6, 1978. CNIL does not produce rules but recommendations. CNIL can decide to suspend a service if any recommendation is not taken into account. Let list some of them which can be a good starting point to have some guidelines to tend to an ethical location service used in European projects:

- each company which proposes a new service handling personal data (c/f location data) has to declare his activity to CNIL. The location service is described in details and is reviewed by CNIL.
- The person using such service has to be informed on the description of the service and on the purpose of the service.
- Each time a person is localized, he/she has to be informed that she/he is being localised and has to be informed on how to stop or to suspend the service.
- The person can give the rights to other persons (family, friends) to know where he/she is located. This consent has to be signed by the person who has subscribed the service.
- The location data has read through a secured access and can be kept on system for a reasonable time: after one month, all location data of a customer has to be deleted.
- Some functions can propose to access the history of past positions: last 4 hours is judged as the maximum delay.
- All backup of database has to be transfer in a secure link and has to be kept in a protected environment and can be accessed only by a dedicated person in the company.
- In company, all computers used to develop or upgrade the location platform service cannot use the reference database containing customer's positions.

Elderly persons are ready to sacrifice part of their privacy to increase their security and to give them more autonomy. For the "live zone" service, location service does not to be felt as electronic bracelet for prisoners but the subscriber is more considered as a patient where location service is a help for medical services and family to protect life of the patient.

We agree with Rialle, that we are waiting to know about the results of the use of GPS that should be published from the different enterprises commercialising these devices and service. From the few data published about fugues in patients with dementia, around 50% of patients not found after 12 hours of having been reported disappeared might be found badly injured or dead. Then we have to add the stress that this implies for families, care givers and other persons involved. So the proper use of GPS has a relevant implication for the benefit of people with dementia and their entourage (Rialle, 2007).

#### 2.5.9 Video Assistance

This issue is closely related to telemedicine, and some legal aspects were commented. The difference is that video assistance is part of tele-assistance, which not necessarily has to be related to medical issues. Video assistance may have a crucial role for telemedicine purposes in some cases but mainly for assistance during daily life activities. Video assistance works mainly through video phones or using video cameras. From the legal point of view, its use is well recognized and for public purposes in most countries it is regulated through laws (as it is explained in the second part of this document)

But from a moral point of view, other questions are raised; can a patient or person feel confident enough if being treated through a video conference. So to achieve this point a tele-health workers need to develop empathy, self assurance and have good communication skills. And from the technological point of view, good quality of image, sound and movement has to be assured. Another issue is how to protect human integrity and value. In electronic tagging the personhood of individuals who are being watched over is under pressure. Modern ICT is a very acceptable means of supplementing care giving, but should not be directly used as the sole substitute for proper personal care and face to face contact. In general this system is well accepted, because people are used to video surveillance in public places, and a new generation of elderly is growing with video communication skills via internet. Even if chat or other options using video conference are for personal use, this might soon be generalized to communicate health professionals with their patients.

Privacy issues related to the video recording and/or audio recording and maintenance of tapes, the storage and transmission of still images, and other patient record data have to be examined, and efforts have to be undertaken to address them to the full extent. The transmission of information over communication lines, such as phone lines, satellite, or other channels, is associated with concerns of possible privacy violations. Another concern in some cases is the presence of technical staff assisting with the transmission procedure at the clinical site (or even at both ends), which could be perceived as a loss of privacy by patients. Patients often are unfamiliar with the technical

infrastructure and operation of the equipment, which can lead to misperceptions of the possibilities of privacy violation during a videoconferencing session.

To conclude, all the above mentioned technologies can be an excellent tool to help patients and persons with some handicap maintain or gain some autonomy and security, but are only acceptable under the ethical framework considered along the chapter. Again new more specific regulations are needed always keeping in mind the existing procedures implemented by the department of Ethics of Science and technology at UNESCO.

## **2.6 Points of view of a an ethical group and a group involved in the development of new technologies for older persons. A pilot study.**

### 2.6.1 Introduction

In the previous section the main problems that may exist when using innovative technologies with older persons and especially those with cognitive problems were exposed. As part of our participation in an European project called MIDAS (Multimodal Interfaces for Disabled and aging Society), we did a small survey. We wanted to have a better idea of the different opinions between opposite groups, if we can call them so. On one side the technical team that is in charge of developing innovative technology and on the other side a group of persons used to debate about ethics in geriatrics. This last group does have a monthly reunion in the geriatric ward and they mainly discuss issues about patients with dementia. Although their opinion could be more focused on this type of individuals, we considered that it was worth exploring their opinion. This is because one of the main goals from this project is focused on the population with cognitive impairment and their caregivers. This group is more at risk and will probably become "Innovative technology consumers".

### 2.6.2 Methodology

We did prepare a small questionnaire. This was a pilot study that is part of the tasks related to the MIDAS project. The questions were issued according to the possible scenarios that were initially proposed for the project. Then we asked one of the organiser of the ethical group meeting to aloud to invite them to answer to these questions. So we came to their regular monthly meeting, we explained them briefly the project and that their opinion would be worthy for us to better understand the acceptability or not of innovative technologies. Then we did translate the questionnaire into English and asked the different participants from the project to answer it.

The query was completely anonymous, we did only make a difference between groups to make at the end an analysis or comparison between their opinions. There were 10 close questions and 9 other open questions with multiple choice answers.

### 2.6.3 Results

We got answers from 16 persons belonging to the ethical group and 15 participating partners from the MIDAS project (21 partners involved including our laboratory). The ethical group is conformed of

persons from different fields and their age varied. In the technical group, most of the participants are men and are involved with technical subjects, only a minority are women (6/20).

Table 2.1 Questionnaire proposed to MIDAS partners and ethical group

	<b>Ethics Group</b>		<b>Technical Group</b>	
	N=16		n=15	
	YES	NO	YES	NO
1 Do you belong to an ethical committee ?	11	5	1	14
2. In your work, have you ever been confronted to an ethical issue?	15	1	13	1
3. Technical aids for daily living can be a risk for human contact	14	2	13	2
4. Technical aids can facilitate the tasks for caregivers in charge of persons with difficulties	16	0	14	0
5. Persons using innovative technologies can become effective in their activities of daily living	15	0	13	0
6. Do you think that a researcher must always ask himself about the ethical constraints before starting?	14	0	12	2
7. Do you think that the fact of asking himself about the ethical limitations can avoid the development of innovations?	11	4	8	6
8. If a researcher proposes to exchange a person at home by a machine to assure a good surveillance of a patient, would you agree?	4	10	6	6
9. Do you think that technical aids can be dangerous?	12	1	10	5
10. Using a camera to evaluate displacement and movements from a person without recognizing her face, can it be acceptable?	5	5	9	3

Then there were questions with multiple choice answers but they were asked to choose the most adapted one to their opinion.

Comments are given below the answers to facilitate the reader's comprehension.

## Questions 11 to 19

*Q.11. According to you: a) it is preferable to keep older people at home with human aids with the risk of caregivers' burnout? b) it is preferable to help the caregiver and the patient with new technologies*

11/15 ethics group and 13/16 from the technical group answered **b**.

**Comment:** good concordance of answers between groups, it is good to see that both share the principle of helping the helper which is crucial to a better result.

*Q.12. Do you think that the development of new technologies to facilitate daily living for elderly...*

a) is a matter of altruism or b) is a matter of commercialization or c) both of them

Ethics Group: b) 2/16, c) 14/16 and Technical Group: a)1/15, b) 4/15, c) 10/15

**Comment:** it is interesting to see that more technical involved persons agree that commercialization is a main issue. The persons admitting this point are probably honest. Otherwise both groups favor the idea of both opinions, altruism and commercialization.

*Q.13 Do you think that using technical aids is:*

- a) useful b) a need) c) indispensable d) to discuss e) useless f) dangerous g) other

	A useful	B A need	C indispensable	D To discuss	E dangerous	F Other
Ethics group	8	1	2	4	1	1
Technical Group	11	9	3	5	1	3

**Comment:** both groups agree in over 50% that technical aids are useful, and it was expected that the technicians would also believe that technical aids are a need.

*Q. 14 Having a system that permits you to identify mimics (without recognizing the face) in order to understand if a person is in pain, sad or happy , would appear to you?*

- A) Useful b) acceptable c) why not if everyone agrees on it d) invasive e) out of question

	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<b>E</b>
Ethics group	1	3	4	1	6
Technical group	6	6	3	4	1

**Comment:** this question is the one where groups have the most opposite opinions. 6/16 persons in the ethics group do completely exclude the possibility of using such a system and only one from the technical group.

Then the opposite, only one person in the ethics group thinks it is useful compared to 6/15 from the technical group. However 4/15 technicians believe it is invasive compare to 1/16 in the ethics group. Because they did exclude the option before. At almost equal proportions they share the possibility of using the system.

*Q. 15. Facilitating communication by telephone or internet through a multi-touch table that permits you also to play cards or visualize photos would seem to you*

- a) useful b) hopeful c) why not d) superficial

	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
Ethics group	0	6	7	2
Technical group	5	2	6	3

**Comment:** none of the ethical group participants thinks this multi touch table can be useful and nowadays there are already many users of multi touch screens mobile phones. However they do not exclude the option of using it since, most persons answered “why not” and that it can be “hopeful” to have such a device. Almost at same proportions groups believe it is superficial and for sure the technical participants at a 5/15 proportion are convinced that such a device is even useful

*Q.16. Having a non humanoid robot at home to survey some tasks like medication intake , or physical physiotherapy would seem to you:*

- a) useful b) hopeful c) not a need d) not even thinkable

	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
Ethical group	6	7	1	0
Technical group	5	3	6	3

**Comment:** two participants in the ethical group did not answer. What is surprising is that 3/15 technical participants exclude completely this option. Then 6/16 think it is not a need compared to 1/15 from the ethics group. Most of the ethic participants think it is hopeful to have such a robot and even 6/16 even believe it is useful. Probably this answers reflect the feeling they have that “caregivers” should be help by any means.

Q. 17. having a **humanoid robot** at home to survey some tasks like : medication intake, physiotherapy exercises would seem to you?

a) useful b) hopeful c) not a need d) not thinkable

	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
Ethical group	2	1	9	3
Technical group	5	4	4	2

**Comment:** this question is interesting, because the fact that the robot to be used should have a "humanoid" appearance changes the answers. For the ethical participants 3/16 exclude the option, 9/16 exclude it partially while answering it is not a need and 2 persons think it is useful. On the other hand the technical participants did not really modify their opinions while adopting a humanoid robot.

*Q. 18. Having a system that would help you with medication intake, that informs you about the doses, indications, adverse effects might be*

- a) useful b)re assures the person c) the person might develop a dependence to it d) dangerous

	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
Ethical group	4	5	4	2
Technical group	10	11	4	1

**Comment:** in this question technical participants used several answers therefore they highly prioritize answers a) and b), which are also well accepted by the ethical group in moderate acceptance. Interesting is that 4 persons in each group did share the opinion that people using the system may get dependent from it, which is a risk in our opinion that is important to take into account.

*Q. 19 Do you think that technical aids can ameliorate autonomy?*

- a) never b) rarely c) sometimes d) always

	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>
Ethical group	0	3	11	1
Technical group	0	1	11	3

**Comment:** here it is evident that both groups agree that technical aids can sometimes help with the degree of autonomy, then as expected 3 persons from the technical group even are more optimistic saying that this is a fact and 3 of the ethical group doubt that this can happen.

#### 2.6.4 Discussion

We did present the frequencies of the answers and since these are opinions that are personal it is difficult to engage a critical argument, but some comments can be done.

In general we can see that opinions between the two groups do not substantially differ. What can be surprising is that only one of the technical participants belongs to an ethical group. This means that there is a lot to do to encourage all persons involved in the development of new technologies to participate more actively in ethical discussions. One of the roles of our laboratory in this European project was mainly to involve all partners to this type of reflexions and discussions. And secondly to act as a modulator along the project to verify that the development does follow the ethical norms that were commented before. It is interesting to see that technical professionals believe as much as the ethical group that technical aids can be a risk, meaning probably that being aware of the risk may help to be precautious.

Participants from the ethical group do not agree with the idea of using "humanoid" robots. This is probably mainly because in the occidental society this is not well seen, people would feel that a robot is replacing another human being. But at the moment that the robot is presented as a "machine" that has some helping functions then it is better accepted.

What was surprisingly is that for the technical partners the fact that the robot has a humanoid appearance did not change their opinion on using a robot.

We are planning to include a group of "end users" to answer the questionnaire, this means older persons coming as outpatients to the clinic. This will give us an idea of the potential acceptability of this type of technologies by the main users.

We are convinced that nowadays such type of interventions during all kind of technological development process are mandatory. Multi disciplinarity is needed and the end users opinion is crucial.

Thanks to the 2 year project SENIOR (Social Ethical and Privacy Needs in ICT for Older People: A Dialogue for Roadmap) that just finished in December 2009, we will have more complete and reliable data on this issue. SENIOR was a support action dedicated to provide a systematic assessment using dialogue as the key instrument to evaluate the social, ethical and privacy issues involved in ICT and Ageing. According to a survey carried out by SENIOR, 51% of surveyed IT companies in Europe have already adopted ethical codes to deal with the complex and multi-faceted issues raised by the information society. Meanwhile, another 31%, which currently do not have

ethical codes, are planning to adopt one in the near future. The sample involved 52 Europe based IT companies, including technical consulting, design and development services, infrastructure provisioning and network management services, internet access and backbone services, telecoms, and software houses (Zen, 2010).

So this is good news and we hope that in the near future ethics would be part of everyday working process.

### 2.6.5 Conclusion

This small query did permit us to better understand what is expected from two groups that belong to opposite sides from the development process.

The fact of expressing these opinions for both groups can be enriching and probably have a regulatory function, this can be an alarm for the researchers and all technical partners involved in the development of technology. Otherwise probably a researcher deeply involved in the technological development might not foresee all risks. It is always necessary to have a broader spectrum to act more properly.

## RESUME DU CHAPITRE 3

Vieillir à domicile est un idéal que peut empêcher le manque et le coût des aides professionnelles à domicile. Une possible solution est l'usage des nouvelles technologies tel que les «environnements intelligents», qui permettent de suivre l'activité et la performance de la personne dans la vie courante. Nous présentons un système développé en collaboration avec France Telecom R&D qui utilise la lecture de signaux électriques venant de l'électro ménager utilisé par les personnes vivant seules à domicile. Selon le moment et les habitudes de la personne, on peut avoir un «pattern» d'activité individuel qui permet la détection d'anomalies. Les données sont mises à disposition via internet pour les professionnels de santé avec un code d'accès. Le niveau d'autonomie est évalué par le type de déplacements faits aussi que par la probabilité d'avoir effectué une ADL, telle que: l'alimentation, se laver, l'usage de WC et le taux d'activité diurne et nocturne. Ainsi, un changement de comportement est détectable par ce système permettant aussi une évaluation de l'autonomie à distance en «temps réel», un avantage très appréciable pour envisager des mesures préventives.

## **CHAPTER 3. USING ENVIRONMENTAL SENSORS TO MEASURE THE LEVEL OF AUTONOMY THROUGH DAILY ACTIVITIES**

### **3.1 Introduction**

One of the great challenges in public health is to find different solutions so that older people can stay at home in safety as long as possible. In most developed countries the governments have created some home care programmes, but they can cover only a part of the population that needs them. The number of care givers is not enough to cope with the challenge and therefore the idea of transforming the environment into an active and intelligent interface that can interact with the person alone at home has become a subject of interest in the last years. The life expectancy in France is 83.8 years for women and 76.7 years for men. At 75 years old, only 5% of the population have ill health and at 80 years 73% still live independently at home. Of the remaining 27%, 14% live with family and only 13% in institutions and for 2020 this number will increase until 25% ([www.cité-science.fr](http://www.cité-science.fr)) But those who are moderately to severely dependant (evaluated by the AGGIR scale) may receive a dividend from local authorities (Vetel,1998).

The challenge of taking care of this home based elderly population is huge and the costs for implementing new home care programmes are threatening the health budget. There is therefore a big interest in trying to develop new surveillance tools that are efficient and cost effective in order to maintain autonomous elderly at home, especially if they live alone( Singla,2009). In addition, the episode of the heat wave in 2003 in France revealed that a lot of elderly people who died at home were not identified as frail or dependent at the beginning. It has been shown that the level of dependency was associated with mortality, mainly in community dwellers (Belmin, 2007). This reality lead to consider the development of social surveillance system but also opens a new interest for simple telemonitoring or assistance devices that might help frail elderly people in such situations (Ohta, 2002).

Several authors have proved the importance of daily health monitoring at home in order to evaluate health status and quality of life. There are also several publications on non-invasive surveillance of ADL performance by new technologies (Dittmar, 2004; Chan, 2005, Rialle, 2002). The main idea is not to use a self-wearable gadgets that could stigmatise or not be worn by some patients when they feel that they still are "fit" enough to continue an independent living at home. Another solution is making the environment "intelligent" enough to inform a remote center about the subject's

performance regarding activity of daily life as proposed by different "smart homes or rooms" (Susuky,2004 and 2006; Rialle,2002; Banerjee, 2003 and 2004).

We report in this chapter the results from our experience with a new method of "surveillance" at home that takes into account the electric signals resulting from turning on and off the lights in the different rooms in the house and from the most commonly used electro domestic appliances at specific periods of time during the day.

The aim of this qualitative study MAPA (Measuring Activity of elderly Persons At home) was to verify the reliability of a non-intrusive surveillance tool and to test its clinical application as well as its acceptability by the population studied.

The aim in this project was to analyse the data and identify: a) the feasibility of the project and b) the accuracy of the data and c) if there was any clinical applicability. In the next paragraphs we present the description of the experimental part that was done.

## **3.2 Methods**

This project was a longitudinal experiment. It was proposed and developed by a multidisciplinary team. The technical support and mathematical modelling was done by an engineer and an ergo-therapist from France Telecom Division Research and Development (R&D), the technical installation by technicians from WATECO CIA and the clinical evaluation and data analysis by two geriatricians from the University Hospital in Grenoble, France.

The experiment was programmed to be done on a 6-month period. Subjects were selected in the Rhône-Alpes Region of France, between May 2005 and august 2005. They were recruited by elderly associations or personal invitation done by the investigators. The persons had to full fill the following:

### **3.2.1 Inclusion criteria**

- Live alone at home
- Have a score AGGIR (Autonomie Gérontologie Groupes Iso-Ressources) >5 (*French scale that evaluates autonomy, commonly used by the social services to decided who needs help at home*) (Vetel,1998 )
- Have a reference person (relative)

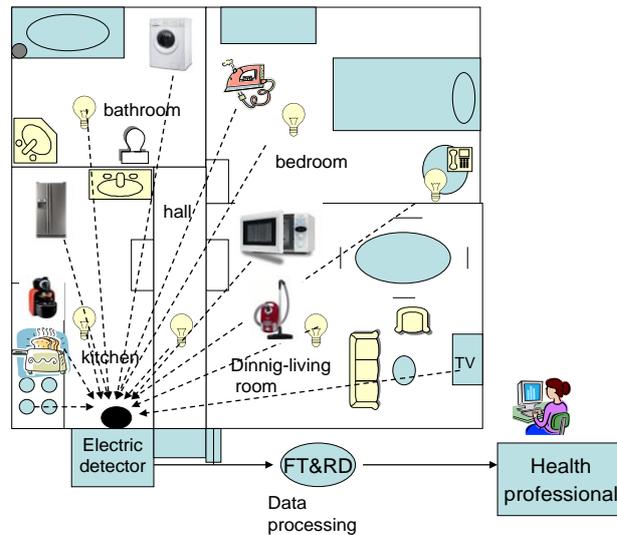
- Being independent for the Instrumental Activities of Daily Living (IADL)
- Have a general practitioner
- Being able to sign up an informed consent

### 3.2.2 Exclusion criteria

- Having severe cognitive impairment (MMSE < 16)
- Persons that leave too often their home
- Persons living with someone else
- Not having a reference person
- Persons susceptible of being not compliant
- Persons being too ill or susceptible of being hospitalised at short term.

### 3.2.3 The system installation

A team from France Telecom installed the ADSL line. The day of installation, the person got an explanation of the system and signed an informed consent. A questionnaire was done on general information about health self perception and physical activity, weekly timetables and whether a person or homecare services came into the house.



**Fig. 3.1 MAPA system, Electro domestic appliances are connected to an electric detector, signals are sent to a data processing center .then to the web**

For the technical part there were three steps;

1. installation of a sensor behind the electric meter
2. installation of an ADSL line
3. detection of the electro domestic tools

This part could be rather long depending on the number of tools to be registered. Each tool had to be turned on and off at least ten times to be detected and registered as its own signal. There were some tools that were marked as complex like the washing machine, dryer, etc. Data were transferred to an external server in France Telecom through WIFI. Then, the person was followed up during one week. After this week, a second questionnaire was given to the subjects in order to record the different activities of the week and verify whether the type of electrical activity detected corresponded to the activity reported by the person. At this same period defaults could be detected and modified if needed. The data were then transferred through *wifi* to a remote center in orange France Telecom & RD, where they were analyzed and thanks to a mathematical modelling converted into useful information that was put on a web page to be accessible to the health care professionals.

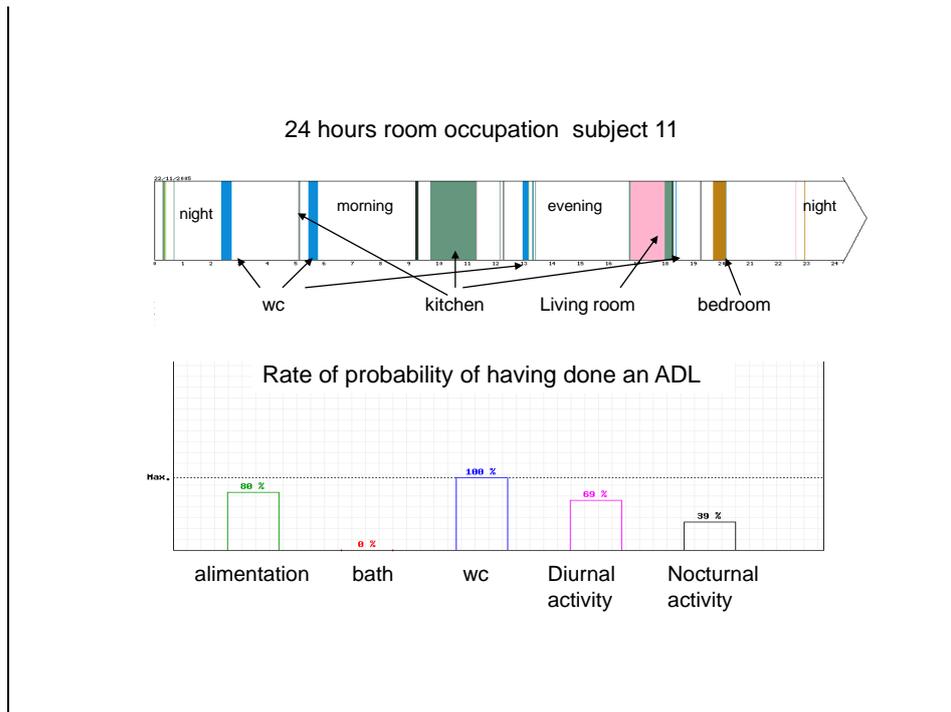
The web accessible information can be analyzed per day, per week, per month or during the whole study period for each subject, which enables the physician to have a broad idea of the person's

performance. For this study we only compared monthly performances. Then weekly patterns were also regarded and in order to differentiate activity during a 24 hour period it was divided into diurnal from 05:00 until 22:30, afternoon/night 22:30 to 23:59 and night 00:00 to 04:59

Data provide different useful information like:

1. Number of displacements, meaning when a person went from one room to another when using the electric system.
2. Type of room that was occupied identified by a colour scale: blue is bathroom, green is kitchen, grey is living room, etc
3. Activities of Daily Living: when taking into account the electric activity from a room lamp plus the electric activity from an electric domestic tool at a certain period of the day for example light in the kitchen between 7 at 8 am, use of the juice press and coffee machine equals the probability of 100% of having "breakfast". But for this purpose it is recorded as "eating". In the same way bathing and toilet use were registered.
4. Whole activity during the day and during the night (00:00 to 04:59)

Sensors were connected to the main electric appliances dedicated to home work that are related to physical activity or indirectly to the IADLs; like using the coffee machine, the vacuum cleaner etc.



**Fig. 3.2\_One day activity of a subject and the probabilities of having done some ADLS.**

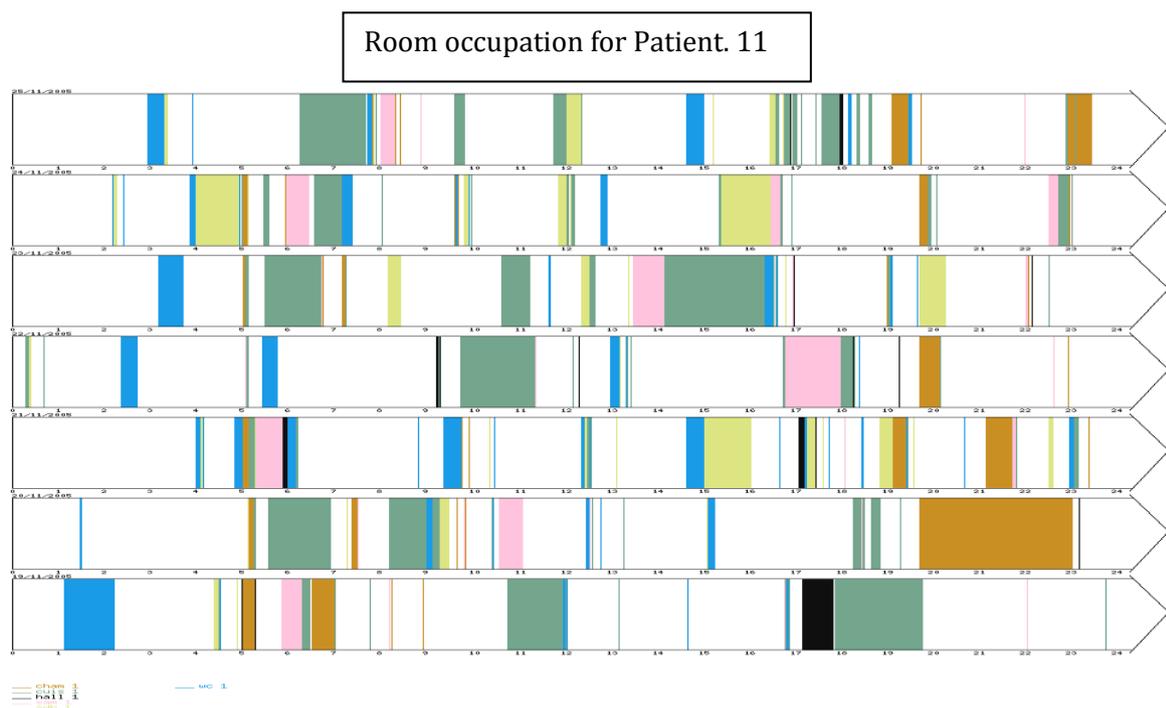
#### 3.2.4 Acceptability of the system

It is mandatory and ethically obligated to evaluate the subject's impressions on the project. It has been reported that usually tele surveillance methods are well accepted by the geriatric population (Banerjee, 2003). For this purpose a questionnaire was designed with three main objectives: 1) self judgement on his age, aging, autonomy and way of living, 2) opinion on their participation in the project and 3) impression on the project once it ended. With key questions like: did you feel observed? Did you feel more secure? Did you change your behaviour?

### 3.3 Results

Data was collected during 6.4 months in average from 13 subjects. The level of activity according to the number of displacements did not change substantially between the summer and winter. They were all living alone with an Instrumental Activity of Daily Living score (IADL) > 7/8. Four of them have a person (caregiver) coming in to help cleaning and 3 subjects benefit from food delivery service. Ten persons were in good health, physically and socially active, 2 were less in shape because of co morbidity and overweight and one subject had mild Alzheimer's disease (MMSE 18/30).

When selecting the option type of displacement we can identify an individual pattern of occupation of the habitat marked by colours. This helps identify a personal pattern. When a person leaves the habitat, no activity is registered and empty intervals can be seen. The colour pattern is interesting, since it is easier for the eye to detect if the person is changing its habitudes, more evident when analyzing the histogram through a whole week. (see fig.3.3)



**Fig.3.3a. Room occupation during one week for a subject. Colours represent the type of room occupied: Blue (WC), brown (bedroom), green (kitchen), black (hall), yellow (bath room), pink (garage)**



**Fig.3.3b Room occupation during one week for a subject. Colours represent the type of room occupied: B brown (bedroom), yellow (living room) green (kitchen), black (hall), violet (garage)**

Activity can be very specific according to the type of activity supposed, but for the real use of the system this data are treated and converted to more useful information and less “intrusive”. From the results we could identify that two subjects had someone living with them during some time because the mean rate of activity doubled, and those with high average numbers had a person coming in to help some days during the week. But this number stayed rather constant.

If we compare this pattern of activity to that from other patients we can easily identify that differences are evident. Also when regarding the activity pattern over a longer period we can identify that this pattern has a tendency to remain stable. This is a good feature for the survey, so that any modification or alteration can easily be detected.

For example the figure on the top (patient 11) shows that during the night the person visits de WC every night and the last night the light was on during one hour, we cannot be sure if he or she forgot to turn off the light but this information could help to better investigate if the person either has a gastrointestinal problem or nicturia secondary to any medical problem. At least if this phenomenon is repeated then medical staff can be alert by an alarm and investigate if there is a real problem or not.

Figure 3.3b shows that this person also turns on the light in the bedroom almost every night, meaning he is awake, only the last night zero electric activity is recorded. Once again a recurrent phenomenon could be compatible with insomnia or other sleep pattern problems that the physician could detect.

The multicolor pattern shows for both persons that they are quite active moving around their house during the day. Therefore a change in this pattern could be more or less easily to detect and help the physician detect a weakening process, fatigue or frailty.

### 3.3.1 Accuracy of the sensors

The average number of electro domestic tools registered per home was 20 (11-28). After the first week of testing, it was confirmed if the person really did use the tools that were registered and the weight was changed if needed and validated. For example using the coffee machine daily would get a maximum of "importance", an iron used twice a week would get a medium level of importance, a lamp over the stove minimum etc. This processing was long and tailored to each subject.

The main problem detected regarding the system itself is that in some habitats the sensors did not register electrical activity for some bulbs or lamps when they were too weak (<40 watts). But a new version of the system has been now developed and this problem has been solved. On the other hand there were no leaks. Because, during periods of absence, no electric activity at all was registered and when more than one person was at home the activity incremented significantly. This can also cause a bias, because the system is not able to make the difference about who is doing an activity, but since it is conceived for persons living alone, this should not be a major problem. For instance for those people, who had caregivers coming punctually to their homes, this event is previously known. So when analysing the activity pattern this has to be taken into account.

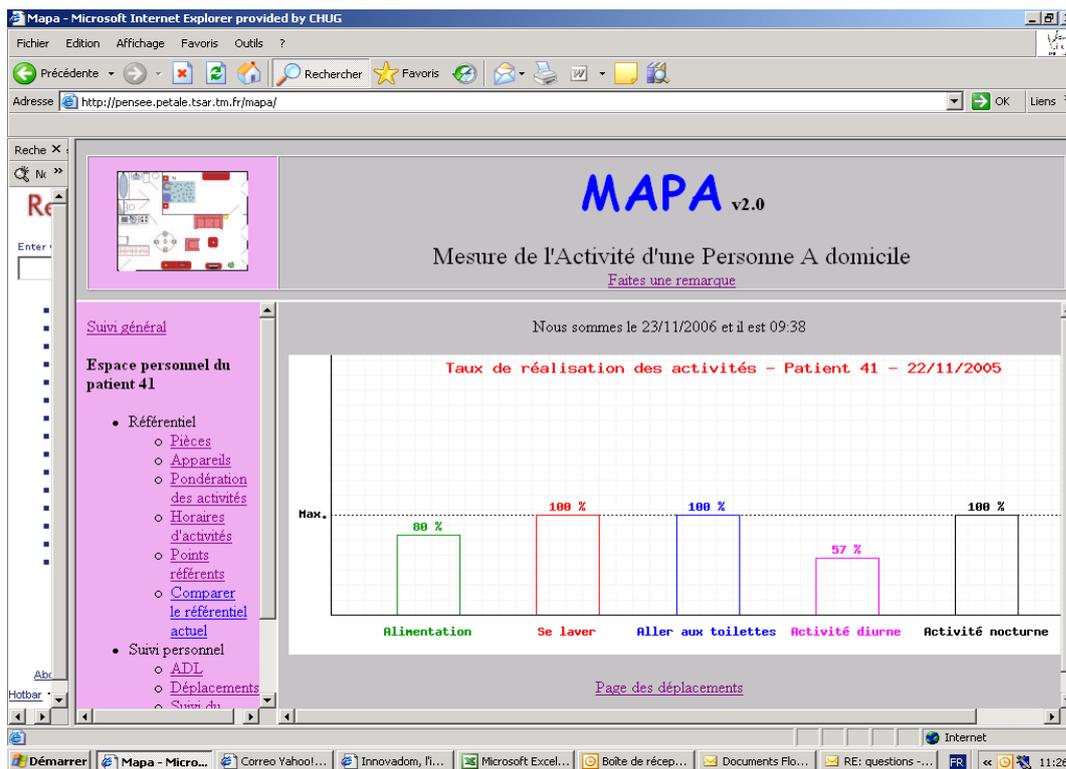
A second problem was that some people do not always turn on the light while going to the toilet during the day or night, so the information for the ADL "bathing" was not applicable for 5 persons and biased for some individuals.

### 3.3.2 Translating activity into ADL

This is probably the most interesting part for us clinicians. Conceiving systems that would only charge medical staff with more work and unknown one would be fastidious, Reading a colourful pattern in a medical consultation would not make sense. So information about autonomy has to be there. A geriatrician is used to handle this variable and for this purpose three variables were analysed:

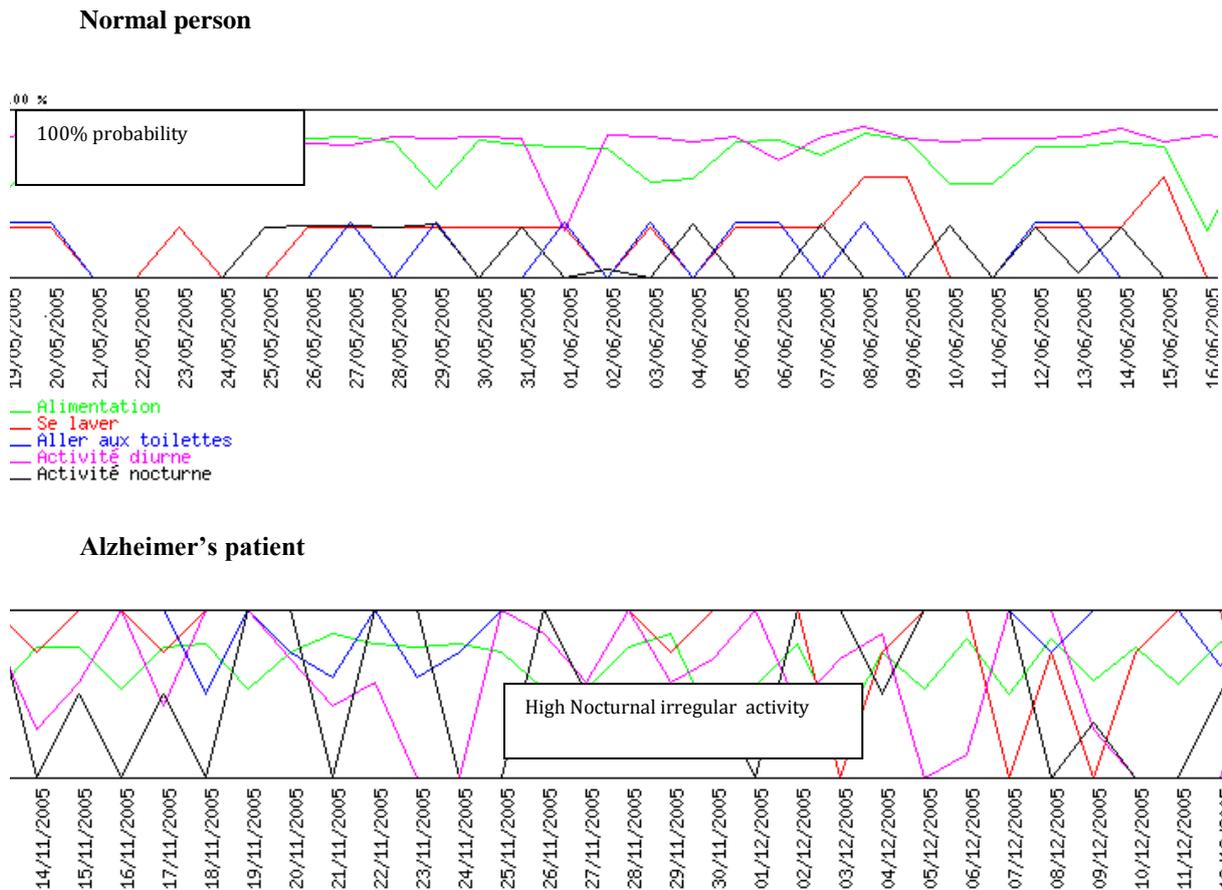
- 1) the presence of the person in a specific room defined by moving into that room while turning on the light,
- 2) then the use of a high importance weighted electro- domestic appliance corresponding to that task and
- 3) the time frame when it happens.

For example "eating breakfast" results from lighting the kitchen between 7 and 9 am and using the coffee machine for that specific person, regarding his habits. The result is the probability of "eating breakfast" that might have happened. Then all different meal times were added and registered as "eating" which can be analyse as a graphic in the "all activities" option. This option permits the clinician to scroll all the evaluation period in a row, showing the dates. Colours are important and the same for all subjects, eating is registered green, using the toilet in blue, nocturnal activity black, etc.



**Fig. 3.4 Graphic showing the rate of probability of daily activities for a specific time period**

In the next figure, we show the comparison between the patient with Alzheimer’s Disease who is very active during the night with a less organised activity at all, compared to a normal subject who has a stable eating and daily activity pattern, with some low intermittent activity during the night. Colour patterns can be helpful to visualize some pattern modification. The colour pattern for room occupation varies between persons according to the type of habitat, so therefore they are not comparable between individuals. But the rate of activity is comparable since variables are rated the same way as shown below.



**Fig.3.5 Comparison of the probability of doing an ADL between a person without cognitive impairment and a person with moderate DAT**

Useful information can be obtained from the data, as for the patient with Alzheimer’s disease who never referred substantial sleep problems. We could identify that during some nights the person was disturbed going to the garage and bathroom, or was watching TV or wandering in the house.

We know from her family physician that the patient started losing weight and became anxious and finally she did fall and broke her hip. These events happened after the study period.

We could detect for some persons that they have a low level of activity compared to the others; Although all patients had a good ADL score (7/8), their individual patterns were completely different. Probably differences are related to morbidity, age or habits, but analysing these variables was beyond our study.

### 3.3.3 Subjects impressions

It is mandatory to have empathy when using new technologies, this is not an easy task, but at least what should be done is to ask "end user" s opinion on several aspects about the technology used.

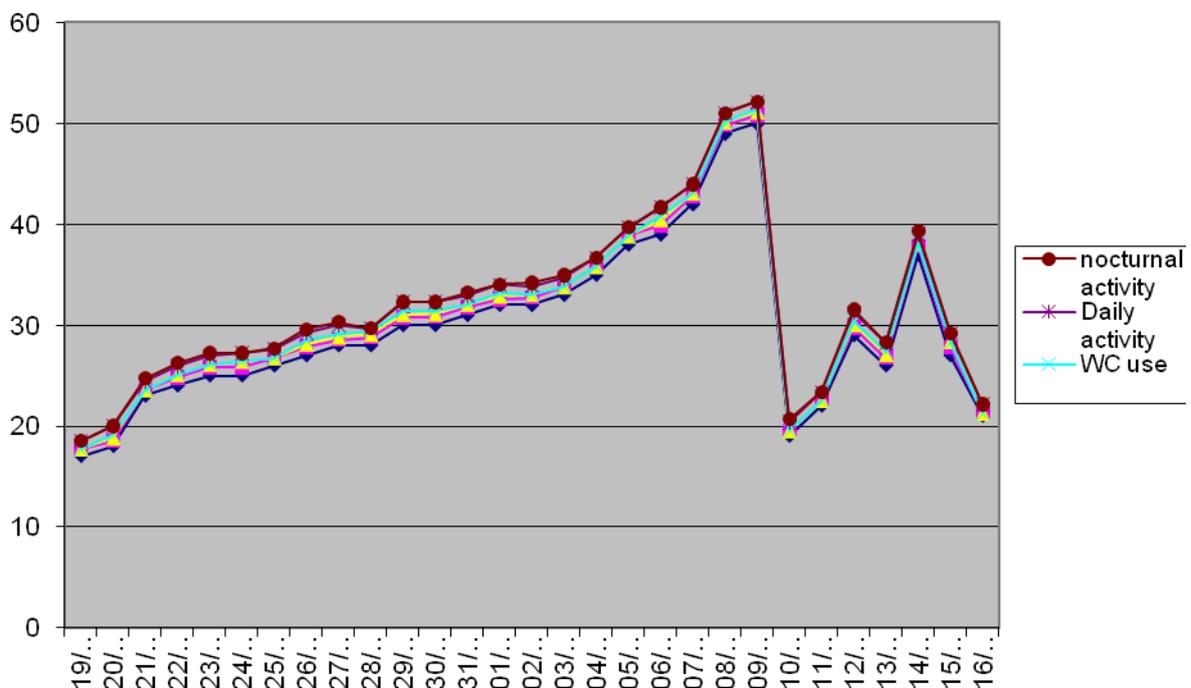
In this case a questionnaire about different domains of the technology was used. Questions were divided in different groups, those regarding the devices and installation of the system and others related to ethical issues; e.g. asking if the person did feel disturbed by the presence of the sensors, the use of data etc. Main or relevant results from this mini survey are the following:

All 13 participants wanted to stay at home as long as possible, 7 participated in the study to help the person who recruited them and 4 to make knowledge advance. For 8 subjects the installation period was too long, 12 referred not to feel observed or surveyed, 10 forgot about its existence once the cables were hidden. All were interested in having feedback on the results and 8 would like to be informed in case of a problem with their autonomy. Twelve believed that it is their physician the best person to analyse the results. In general the negative impressions were regarding the installation period and having in some rooms too many cables.

### 3.4 DISCUSSION

Some authors including our group have registered the level of total activity, divided in daily or nocturnal, which has proved to be useful when using different technologies, infra red sensors, doors and windows and electricity. Most publications are based on identifying a pattern of normality usually defined by the mean  $\pm$  2SD and when outliers are detected an alarm is given. (Susuky, 2004 and 2006; Gill, 2006; Nakano,2002)

MAPA permits to easily identify a pattern of normality either by the coloured graphic of displacements and by the rate of activity calculated, as shown on the figure. The health actor can access this information through internet from his office. This can aloud the physician or medical staff in charge from the patient to access anytime using a log in and password to the decrypted data of the patient. The importance for a geriatrician for example of having this precious information is that is real and valid. Then elderly persons during a common medical consultation may tend to diminish their disability to accomplish some task or their level of "tiredness" because are afraid of being told that it is time to have a caregiver or to go to an institution.



*Fig.3.6 Activity transformed to the probability of having done daily activities on a daily basis.*

So the physician could have reliable information about the level of autonomy of the patient which is a crucial indicator of the general health status of the patient, physically and mentally. For example through MAPA the doctor can evidence that for the last two weeks a person is constantly watching TV at 2 am, and that during the morning no activity is registered in the kitchen. So he can ask the patient about his or her sleeping habitudes and investigate about precise problems. At least the system raises de question about a problem often ignored or not recognized as important by patients. If it is the case the doctor could discuss the reason why this is happening and try to find a solution for insomnia. But if the person says that everything is fine and feels that changing his nocturnal rhythm is not relevant or he does not want to talk about it, then from an ethical point of view, this could be questionable. Once again we raise the importance about the informed consent and the adequate use of sensitive data. So the physician has to be sure that gathering more information about the sleep pattern or better say about the level of nocturnal activity pattern is really necessary for the patient's management. Elderly people seem to keep living styles rather stable, which helps the person in charge of observing the data to recognize abnormalities.

Considering wrist actigraphy, (Sommeren, 2007) showed that weekly patterns are more a less stable and that inter-week variability can be identified. In general the more registers about nocturnal activity we have the more reliable information might be. But it is also possible to detect abnormalities or alterations in the rhythm of daily living in a more accurate way. The system gives the possibility to access a table giving the number of displacement for a time period and see if the rate has augmented or diminished (data not shown).

A group in Japan showed the rhythm of daily living of a 72y old woman at home through different types of sensors; mainly through movement recognized by infra red and photoelectric sensors, and electrical activity coming from the TV. They were able to differentiate during a day four periods: sleeping, getting up and breakfast, indoor activities/ going out and dinner/going to bed (Susuky, 2007) but also from patients in a nursing home (Susuky, 2006).

With MAPA the main difference with other systems, is the fact of seeing the probability of having done three main activities of daily living: eating, bathing, or going to the toilet.

To resolve the no detection of some lights in the bathrooms, a more efficient 'sensor' will be used or either an automatic switch can be installed. Another possibility is to add an infra red movement detector. This would also diminish the bias caused by not turning on the lights during the day or because enough luminosity during the night coming from outside the house. It was not done, because the main idea was to validate MAPA alone and to test its accuracy. Another advantage is

that details on activity can be shown, for example if the person uses the vacuum cleaner, does ironing or cooking with the oven. It gives an idea of the subject's habits, since only electric home tools are detected, but is an indicator of their autonomy for instrumental activities.

Future applicability:

Information on using the toilet and bathing are crucial. In other publications it has been reported that an augmented frequency of toilet use can give an idea of a possible urinary infection or an episode of diarrhea. And it is well known that bathing disability is an independent risk factor for frailty and also its importance in the hierarchy of losing this capability is well known, being even a marker for the disabling process (Gill, 2006). If the total number of displacements diminishes, or if the person stays for longer periods in his bedroom for example, this can be an indirect sign of possible sickness, but the system should mainly be capable to detect early enough loss of autonomy. Underestimation of losing autonomy is well known, especially if elderly people want to justify their capabilities to be able to stay at home. MAPA can then help identify whether the global level of autonomy or a specific task are affected.

This system could help to evaluate the need of introducing Assistive technology since people tend to underestimate their needs for example: smoke detectors for people forgetting to turn off the electric stove, door alarms for people living the house rather often or during the night.

Regarding the evaluation of the night activity and sleep, MAPA can give also useful information, not only because of the rate of activity during the night period, but also giving details like shown for a perturbed night from our patient with Alzheimer's Disease. Similar nights of insomnia with different types of activity can be seen in other subjects. In case of wanting to be more accurate for some subjects an infrared sensor close to the bed could be installed, as has been done in other studies (Nakano, 2002).

The MAPA system was well accepted. Most individuals agree with the idea of a low-invasive tool since there are no cameras, which is a known concern for this population, but as Demiris reported elderly persons show overall a positive attitude towards devices and sensors, once they understand their use (Demiris, 2004). Only two persons thought that there were too many cables around. Some of them were concerned about the possibility that their electricity bill might increase too much. In fact the cost calculated per month is about 30 euros apart from the material. Available alarm systems with accelerometers nowadays are more expensive.

These results are encouraging but a new project should be planned to follow autonomous elderly person at home for a longer period. Only in this way we can be able to recognize if the system is able to detect frail elderly before an adverse event happens, like was the case from the person with

mild DTA. Susuky T published the use of infrared sensors at home, he found that a shorter sleep time and the number of outings were highly correlated with early dementia (Susuky T,2007). With our system we could also identify that the patient with DTA living alone also had a different type of activity as shown before. This might be also a new way to approach autonomy loss in patients with dementia living at home.

As Tang stated the integration of smart homes and telecare in different axes will be a cost effective solution (Tang, 2000).

We have shown an environmental system at home that is capable of differentiating levels of activity and even autonomy. It can also be able to help a clinician identify the difference between a "normal" pattern of activity and that of a person with moderate dementia with a disruptive pattern. Now we will introduce the second experimental part about the environmental sensors in a hospital room to quantify activity, "environmental actigraphy.

## RESUME CHAPITRE 4

L'actimétrie environnementale en milieu hospitalier par l'usage des capteurs infra rouges a déjà été validée. Le système est donc utilisé pour évaluer l'activité nocturne chez des patients déments et la comparer aux non déments. Les variables étudiées étaient le niveau d'autonomie et la présence des symptômes dépressifs. Le taux d'activité nocturne, la variable «à expliquer» est plus élevé chez le sujet dément, mais il diminue en présence de symptômes dépressifs associés, contrairement au sujet sans trouble cognitif qui, en présence de symptômes dépressifs, voit son activité nocturne augmentée. Le niveau d'autonomie influence aussi l'activité nocturne dans les deux groupes. Ces résultats se basent sur une population de 33 patients hospitalisés dans un service de gériatrie au moins pendant 8 nuits consécutives. Ce système peu invasif peut être utile dans les unités psycho gériatriques, car l'évaluation de l'activité nocturne est désormais une variable pertinente dans le suivi des patients avec troubles du comportement nocturne.

## **CHAPTER 4. USE OF ENVIRONMENTAL ACTIGRAPHY IN THE HOSPITAL**

### **Measuring nocturnal activity through Passive Infra Red Sensors (PIRS) in hospitalized patients with dementia.**

#### **4.1 Introduction**

Passive Infra Red Sensors (PIRS) are a common type of activity sensors with a broad use in the environment. They are mainly used for automated doors everywhere and nowadays people do not even realize how many of them are detecting their activity in daily life. Our laboratory LI2G developed in collaboration with the INSERM U 558 a system called GARDIEN® (Gérontologie Assistée par la Recherche et le Diagnostic des Incidents et des Errances Nocturnes), (Banerjee, 2003 and 2004) . This system PIRS because this type of sensors are stable, robust, not expensive and have a very low error rate. PIRS are used in most automatic doors in the commerce or buildings, therefore elderly persons are also used to them. In fact the advantage with GARDIEN® is that the PIRS do not start an automatic visible activity for the individual like opening a door or a window. Their only task is to detect movement in a determined perimeter/ surface in the room and send the signal to a computerized system. In this way the strategic position of the eight PIRS covers the total surface of the room. One PIRS is positioned at the corner at 1m from the floor in order to detect if the patient falls in the room. So it's sudden "no activity detection" could function as a fall detector is previous movement was registered.

Infrared sensors were chosen because of the advantage of being part of the environment instead of the worn devices that are not very well adapted for demented patients as it happens with pendant alarms, arm-bands, etc.

In new versions of the device they have introduced a lock-up security system in the bracelets to avoid that the demented or agitated patient takes it off. But another question then could be. What happens if the fact of trying to get rid of the device could also be a source of agitation? For

instance, we demonstrate that ambulatory arterial pressure measurement device can enhance sleep fragmentation in elderly patient

We believe that with the new advances in technology, the development of «intelligent» environments can be more appropriate to survey those patients either at home or in institutions.

At the beginning in our laboratory the system was validated within a group of elderly patients. Then comparing the results produced by Dr Banerjee and Couturier to other data from the literature helped understand that the system was able to identify different patterns of activity according to the different levels of dementia. This means that nocturnal activity may change depending on the degree of cognitive impairment. This in fact has been confirmed with worn devices in different kind of populations (Banerjee, 2004.) This was expected but the idea of having an objective marker was the most interesting part.

## **4.2 Objectives**

### **4.2.1 Main objective**

Verify through environmental actigraphy that nocturnal activity in patients with dementia varies according to the severity of cognitive impairment.

### **4.2.2 Secondary objectives**

Demonstrate the relation between the level of autonomy according to ADLs, the presence of depressive symptoms and nocturnal activity measured by environmental actigraphy.

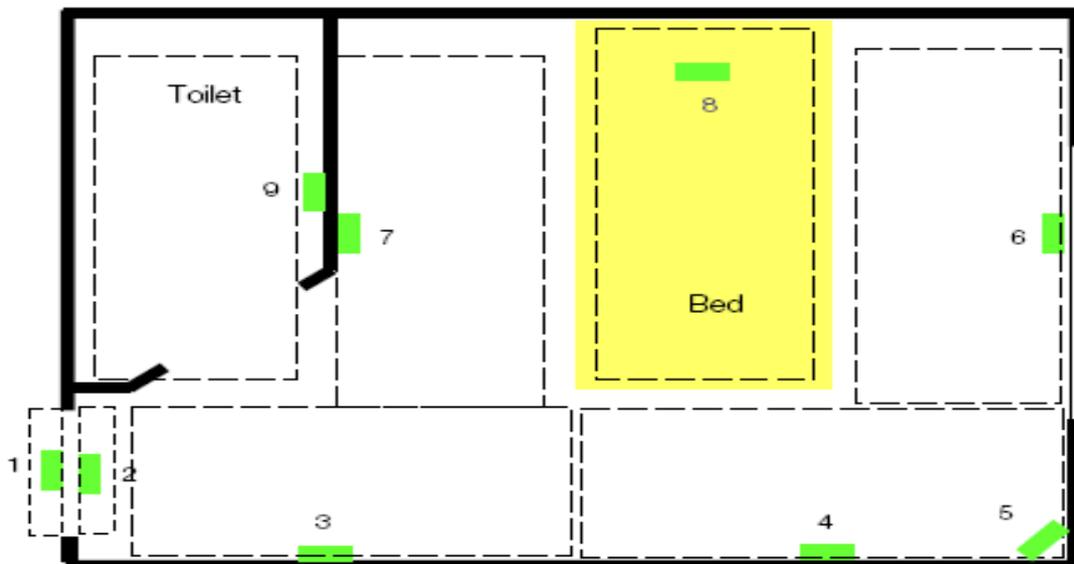
## **4.3 Hypothesis**

- a) There is a positive correlation between the degree of severity of cognitive impairment measured by MMSE and the level of Nocturnal activity measured by environmental actigraphy.
- b) There is a negative correlation between the level of autonomy measured by ADLs and the level of nocturnal activity measured by environmental actigraphy.
- c) There is a negative correlation between the presence of depressive symptoms measured by the GDS and the level of nocturnal activity measured by environmental actigraphy.

## **4.4 Materials and methods**

### 4.4.1 The system

A hospital bedroom (3m x 3m) for a single patient was selected for the study. The system G.A.R.D.I.E.N.® is installed in that room and the 9 PIRS were installed in strategic places to cover the total surface of the room. (Figure 4.1). The sensors were numbered as 1 (entry-outside), 2 (entry-inside), 3 (wall), 4 (wall-window), 6 (window), 8 (bed), A (centre), and C (toilet). Only sensor 1 was situated just outside the room. Each sensor was activated (on-off) by human movement in its field of view, covering a floor area of approximately 2m x 1m.



***Fig- 4.1 Disposition of 9 Passive Infra Red Sensors (PIRS) in the room***

Sensors were connected through cables to an I/O parallel card of a PC, kept in a separate observation room. The PC automatically captured data from the different sensors every day, but for the purpose of this experiment we take into account data from 00:00 until 06:00 the following morning.

After the surveillance period, a computer program analysed the signal data from all sensors by the sequence of activation-deactivation, registered in a log file and, using artificial intelligence, generated an automated report (*activity chart*) showing different activities (displacements) in the room with indication of the date and time of the start and the end of each displacement.

The system can generate two types of reports that can be useful for the clinician. A detailed one where each detected movement is registered and codified according to the duration and the time when it happened. This can give in detail information about very precise periods of time. And there is also the short report that gives an overview of the main activity phenomena that occur during the period registered. The system once lunched registers non- stop but to analyse the data we can choose different time options.

The reason is that we are first interested in nocturnal activity. Even if the system is able to make the difference when other people are in the room, we did prefer to avoid possible data contamination and registered only at that time frame. In the ward, nocturnal staff does usually a round at midnight, another around 4 am and then around 6 am.

The 'duration' of activity plotted against each night was used to follow-up the patients in the long-term. The 'frequency' of sensor activation was printed after each night as an *actigram*, which along with the activity chart was used to analyse that particular night's activity. An *actigram* plots the time in the x-axis (in 15-minute intervals), the number of times a sensor is activated during each 15-minute interval (called frequency of sensor activation) in the y-axis, and the different sensors in the z-axis. In the activity chart, the duration of bed, room and toilet activity were given as well as the duration of total nocturnal activity.

#### 4.4.2 Patients Inclusion

All patients were usual hospitalized patients from the geriatric clinic. They were in the sector where the PIRS system was installed. For the first patients that correspond to the first pool of patients that were included they had to be hospitalized for one week before being registered. It was with this cohort of patients that the system was validated. Then for the second group of patients that were

added, criteria were less severe since we had some evidence that some variables were not relevant for the study purpose.

a) Inclusion criteria

1. The patient or his legal guardian had to give a signed informed consent
2. The patient should be able to walk and move freely in the room.
3. The patient had to be hospitalised for at least 8 nights
4. Patients With or without cognitive problems

b) Exclusion criteria

5. patients in palliative care or end of life stage
6. patients with nosocomial infectious
7. patients with acute cardio respiratory problems
8. bed ridden patients
9. patients hospitalised for < 8 nights
10. patients with behavioural problems incompatible with the system

#### 4.4.3 Statistical analysis

Sample size or N = 33 subjects; 11 subjects without depressed status variable were not analyzed. The "normal patient" was defined with a MMSE above and no dementia

##### 4.4.3.1 Variables

The main variables that were retained for the analysis are the following with their operational definition. (Scales are shown in the annexes.) and were commented in previous sections.

- *Cognitive impairment*: defined according to the MMSE being positive if < 23.
- *Presence of depressive symptoms*: defined by the GDS if >12

- *Autonomy level*: defined by the ADL cutoff point >3..

Outcomes:

- 'Mean Nocturnal Activity' over 8 nights (cross-sectional analysis).
- 'Nocturnal Activity' measured repeatedly for 8 nights (longitudinal analysis).
- Exclusive inpatient movements detected by PIRSs placed at a height of 2-3 m above the ground in two 3 x 3 m<sup>2</sup> patient bedrooms at the university hospital in Grenoble, France, between 00:00 and 06:00 hours, expressed in seconds as total (cumulative) nocturnal activity including bed, toilet and room activity.

Exposure variable: two groups consisting of 'normal cognitive function' and 'cognitively impaired' obtained by categorizing MMSE score (0-30) with cut-off 24/25 and no dementia (DSM IV criteria) named as cognitive status in this analysis.

Covariates selected in the final stage of analysis:

- (i) ADL score (continuous, 0-6).
- (ii) Depressed status (yes / no) obtained by categorizing the GDS score (0-30) with cut-of 14/15.
- (iii) Nights (in longitudinal analysis only).
- (iv) Interactions (dépressif state x cognitive state).

Covariates not considered in the final stage of analysis: antidepressants, hypnotics, neuroleptics, weight, prosthesis, continence, because they were not significant in preliminary regression analysis using backward selection as well as in univariate analysis.

Data were pooled from two researchers (A: N = 21 and B: N = 12); the covariate 'researcher' was not a significant covariate as well. Approach to missing data (for the outcome measures only): approximately, 6% of data were missing, for which mean values for the remaining nights were inputted in the longitudinal analysis.

All analyses presented were carried out with SAS<sup>®</sup> 9.1.3 (SAS Inc., Cary, NC, USA), R 2.9.0 (CRAN) and WinBUGS 1.4.3.

## **4.5. Results**

The total pool of patients was of 45 registered with GARDIEN<sup>®</sup>. We could not have a greater number as wanted at the original protocol due to several reasons, at the beginning of the project there were two rooms equipped with the GARDIEN<sup>®</sup> system but then due to the installation of the air climatization, the rooms were blocked for one month and then one of the systems got damaged and could not be repaired.

Not all subjects were included in the data analysis. The reason for drop outs was mainly that we did not resemble 8 continuous nights for these patients, because of technical problems, like electric blackouts during the installation of the air cooling system.

Another point is that due to internal and administrative issues a patient was hospitalized in the equipped room for over 3 months. Since we found some interesting results, we present this case separately in chapter 5.

As explained before, having as previous experience the publications done with the first pool of patients, we knew that some variables were not statistically relevant for this part of the study. An example is the NPI score that did not show relevancy in the first part of the study done by Dr Banerjee.

### **4.5.1 Studied population characteristics**

The final population use for the analysis was conformed of 33 patients (population including the depressed symptoms variable). 25 subjects had cognitive impairment and 8 controls without cognitive problems. There were 17 women and 16 men; the mean age for the whole group was 80.09 years, being 82.3 for women and 77.68 for men. According to the type of dementia there were:

Alzheimer's disease, 11 cases; Vascular dementia and mixed dementia, 8 cases, Lewy Bodies dementia type 5 cases and fronto temporal dementia 1 case

The principal demographic characteristics are shown below in Table 4.1.

**Table 4.1. Demographic & clinical characteristics of the sample population by exposure group:  
N = 33**

<b>Characteristics</b>	<b>Cognitively impaired (N = 25)</b>	<b>Normal cognitive function (N = 8)</b>	<b>P-value</b>
MMSE, mean (SD)*	14.0 (5.0)	26.6 (1.2)	<0.01
ADL, mean (SD)*	3.5 (1.4)	4.7 (1.4)	0.04
Weight, mean (SD)*	57.8 (9.5) <sup>†</sup>	60.8 (14.8)	0.82
Mean nocturnal activity (seconds), mean (SD)*	1593.3 (1393.2)	548.2 (536.8)	0.04
<i>Disability, N (%)<sup>‡</sup></i>			
ADL ≤3	10 (40.0)	1 (12.5)	0.22
ADL >3	15 (60.0)	7 (87.5)	
<i>Depressed, N (%)<sup>‡</sup></i>			
Yes	10 (40.0)	4 (50)	0.70
No	15 (60.0)	4 (50)	
<i>Prosthesis, N (%)<sup>‡</sup></i>			
Yes	4 (16.7) <sup>§</sup>	3 (37.5)	0.33
No	20 (83.3)	5 (62.5)	
<i>Hypnotics, N (%)<sup>‡</sup></i>			
Yes	21 (84.0)	5 (62.5)	0.32
No	4 (16.0)	3 (37.5)	
<i>Antidepressants, N (%)<sup>‡</sup></i>			
Yes	10 (41.7) <sup>§</sup>	3 (37.5)	1.00
No	14 (58.3)	5 (62.5)	
<i>Neuroleptics, N (%)<sup>‡</sup></i>			
Yes	14 (58.3) <sup>§</sup>	1 (12.5)	0.04
No	10 (41.7)	7 (87.5)	
<i>Continence, N (%)<sup>‡</sup></i>			
Incontinent	2 (8.0)	1 (12.5)	0.04
Partially incontinent	11 (44.0)	0 (0.0)	
Continent	12 (48.0)	7 (87.5)	

\* Kruskal-Wallis test, <sup>†</sup> N = 23 ; <sup>‡</sup> Fisher test , <sup>§</sup> N = 24

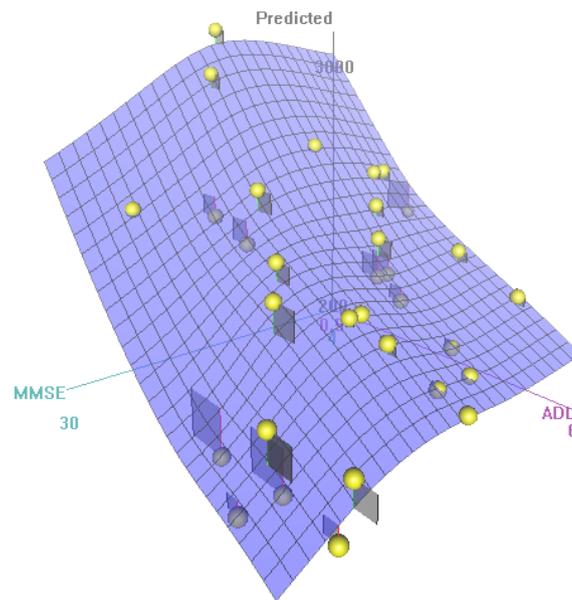
#### 4.5.2 Cross-sectional analysis (GLM)

**Table 4.2** Parameter estimates for the cross-sectional analysis with mean nocturnal activity as outcome; N = 33

Characteristic	Gamma model			Negative binomial model		
	Exponentiated estimates	95% CI	P-value	Exponentiated estimates	95% CI	P-value
Cognitive status						
Cognitively impaired	4.3	1.7-10.9	<0.01	4.3	1.7-10.9	<0.01
Normal	1.0 (referent)			1.0 (referent)		
Depressed status						
Yes	3.1	1.1-8.8	0.03	3.1	1.1-8.8	0.03
No	1.0 (referent)			1.0 (referent)		
ADL	0.8	0.6-1.0	0.02	0.8	0.6-1.0	0.02
'Depressed X cognitive' status	0.3	0.1-0.8	0.02	0.3	0.1-0.8	0.02
Scale / dispersion parameter	1.8	1.2-2.8	na	0.6	0.3-0.8	na
GOF (value / DF)	0.7			1.3		

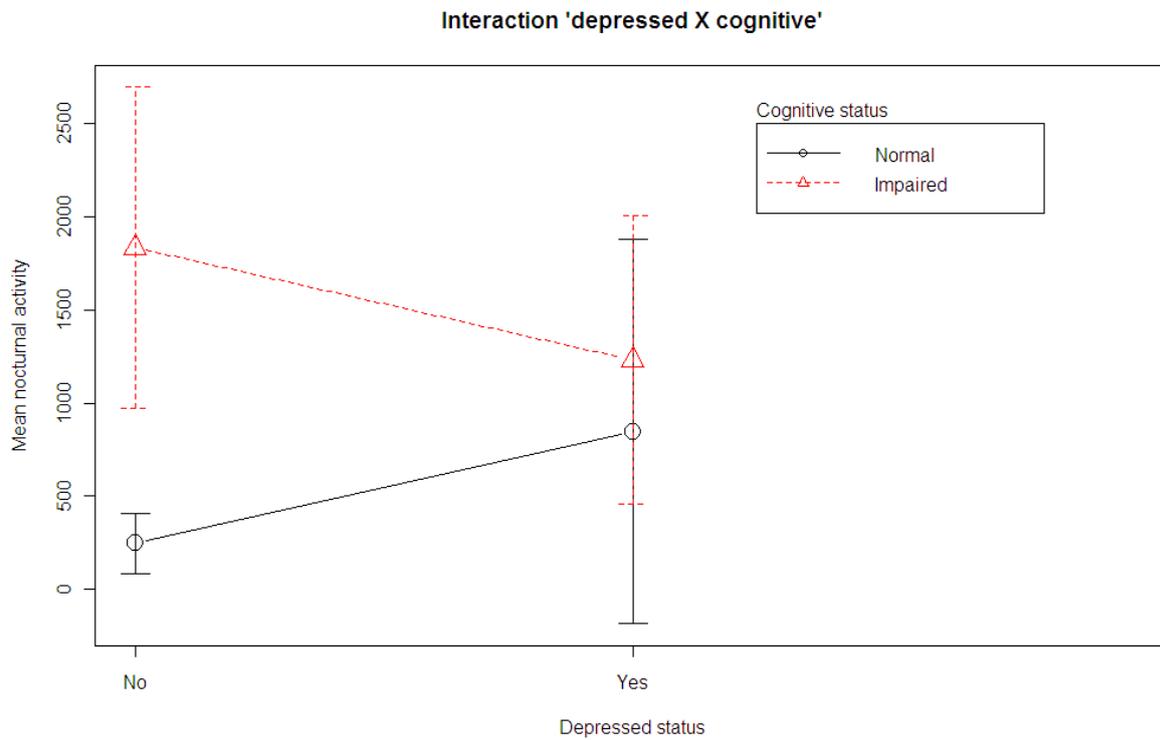
Note: scale / dispersion parameter is not exponentiated; values are rounded-off to one decimal value

- Mean nocturnal activity is 4.3 times elevated in the cognitively impaired group with respect to. the normal cognitive function group.
- Mean nocturnal activity is 3.1 times elevated in the depressed with respect to. the non-depressed.
- However, the exponentiated interaction < 1, meaning that being depressed causes paradoxically decreased mean nocturnal activity in the cognitively impaired group.
- Mean nocturnal activity decreases with disability (ADL), *i.e.*, 20% decrease with each unit rise in ADL score.
- Although the (exponentiated) parameter estimates (95% CI) of the two models are very close, the GOF in the gamma model is better, which is our reference model for this analysis.



**Figure 4.2 shows the 3-D relation between ADL, cognitive status and mean nocturnal activity**

- Figures show the relative importance of disability (ADL) and cognitive status with respect to predicted mean nocturnal activity, with disability having more pronounced effect than cognitive status.
- Figures are adjusted for the depressed status and the interaction 'depressed status X cognitive status'.
- The yellow balls represent the squared residuals.



***Figure 4.3 shows the interaction 'depressed status X cognitive status'***

### 4.5.3 Longitudinal analysis

**Table 4.3** Parameter estimates for the GEE analysis with nocturnal activity as outcome

<i>Characteristic</i> <i>N= 33</i>	Gamma model			Poisson model		
	(empirical; exchangeable working correlation)			(empirical; exchangeable working correlation)		
	Exponentiated estimates	95% CI	<i>P</i> -value	Exponentiated estimates	95% CI	<i>P</i> -value
<i>Night</i>	1.0	0.97-1.03	0.94	0.98	0.96-1.01	0.25
<i>Cognitive status</i>						
<i>Cognitively impaired</i>	4.1	2.1-8.0	<0.01	4.7	2.4-9.3	<0.01
<i>Normal</i>	1.0 (referent)			1.0 (referent)		
<i>Depressed status</i>						
<i>Yes</i>	3.5	1.7-7.2	<0.01	2.8	1.1-7.4	0.04
<i>No</i>	1.0 (referent)			1.0 (referent)		
<i>ADL</i>	0.8	0.7-0.9	<0.01	0.8	0.7-0.9	<0.01
<i>'Depressed X cognitive' status</i>	0.3	0.1-0.7	<0.01	0.3	0.1-1.0	0.05
<i>Correlation</i>	0.4			0.4		
<i>GOF (value / DF)</i>	1.1			1350.2		

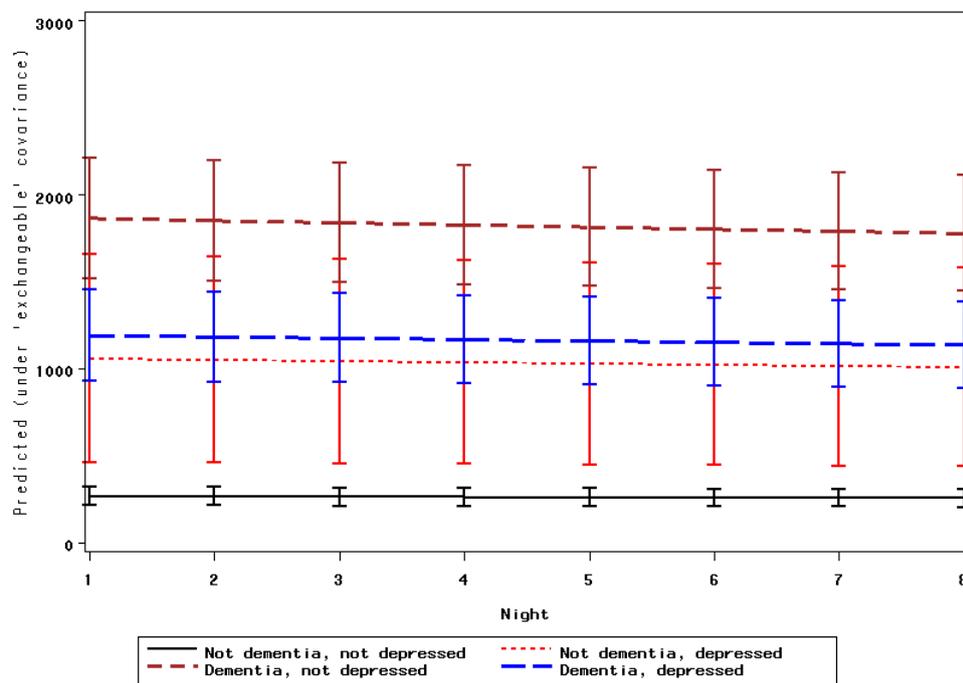
#### 4.5.3.1 Marginal model (GEE)

Note: correlation coefficient is not exponentiated; values are rounded-off to one decimal value (except night)

- Night (time) variable is not significant.
- Poisson model is kept **only** for comparison; it points towards a significantly high overdispersion owing to its poor GOF.
- Quasi-Poisson model is not shown here.
- Negative binomial model did not converge.
- As model-based CIs differed, only empirical ('sandwich') estimates are presented.

- Exchangeable (or compound symmetry) working correlation estimates are shown here; other working correlation estimates (independence, autoregressive and unstructured) are not shown, which are very similar.
- In the non-depressed, cognitively impaired patients had 4.3 (2.2-8.7, 95% CI;  $p < 0.01$ ) higher mean nocturnal activity than normal patients; whereas in the depressed, cognitively impaired patients had 1.1 (0.5-2.5, 95% CI;  $p = 0.87$ ) times higher mean nocturnal activity than normal patients, which was not significantly different at all.

GEE: predicted nocturnal activity (seconds) by group, 95% CI



**Figure 4.4 shows predicted mean (GEE) nocturnal activity (95% CI) by 'depressed status X cognitive status'**

- 'Dementia' / 'Not dementia' in the legend is to denote the groups, 'cognitively impaired' / 'normal cognitive function', respectively.

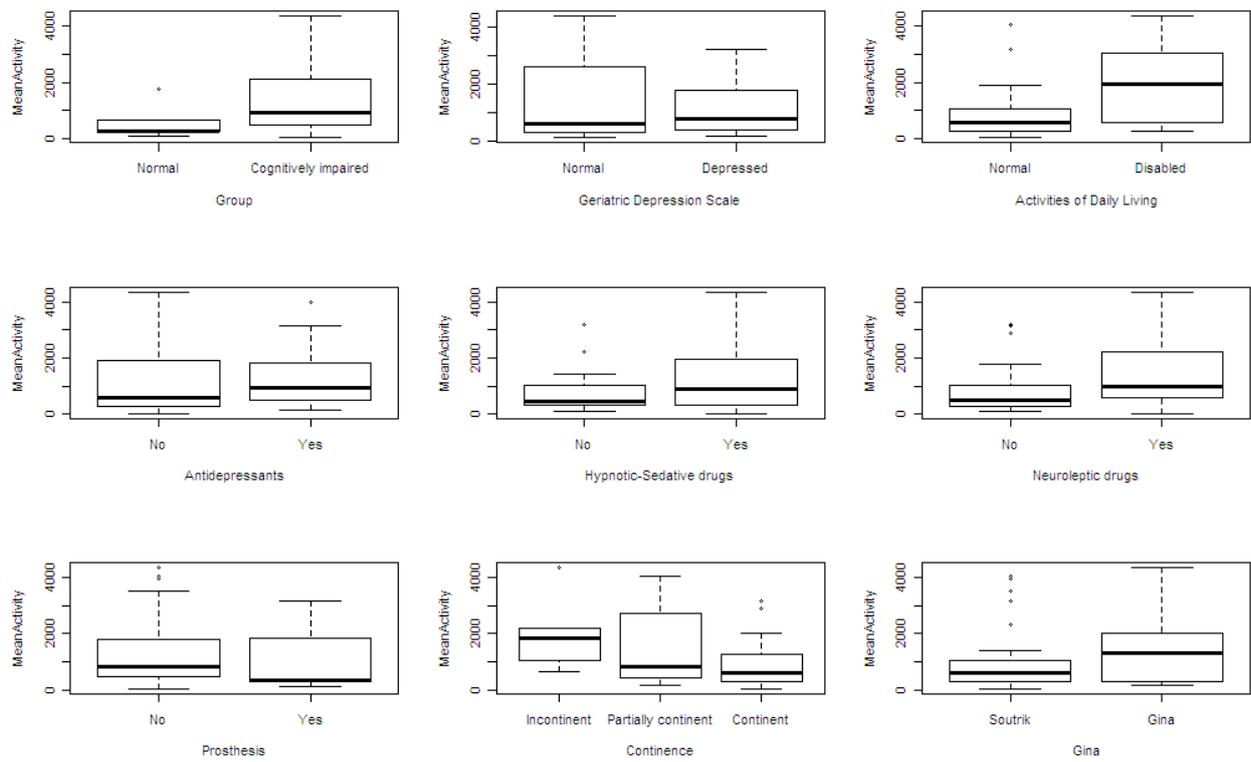
#### 4.5.4 Comparison of two subpopulations according to depressive symptoms presence

##### Univariate

Patients not having (N = 11) and having (N = 33) the depressed variable were compared (Kruskal-Wallis or Fisher 2-tailed test) in terms of population characteristics in separate univariate analyses. The variables that were compared: MMSE, ADL, *prosthesis*, *antidepressants*, *neuroleptics*, hypnotics, continence, *weight* and mean nocturnal activity (outcome). None of these variables were significantly different between the two groups. One patient who did not have any covariate was excluded in this analysis.

##### Multivariate:

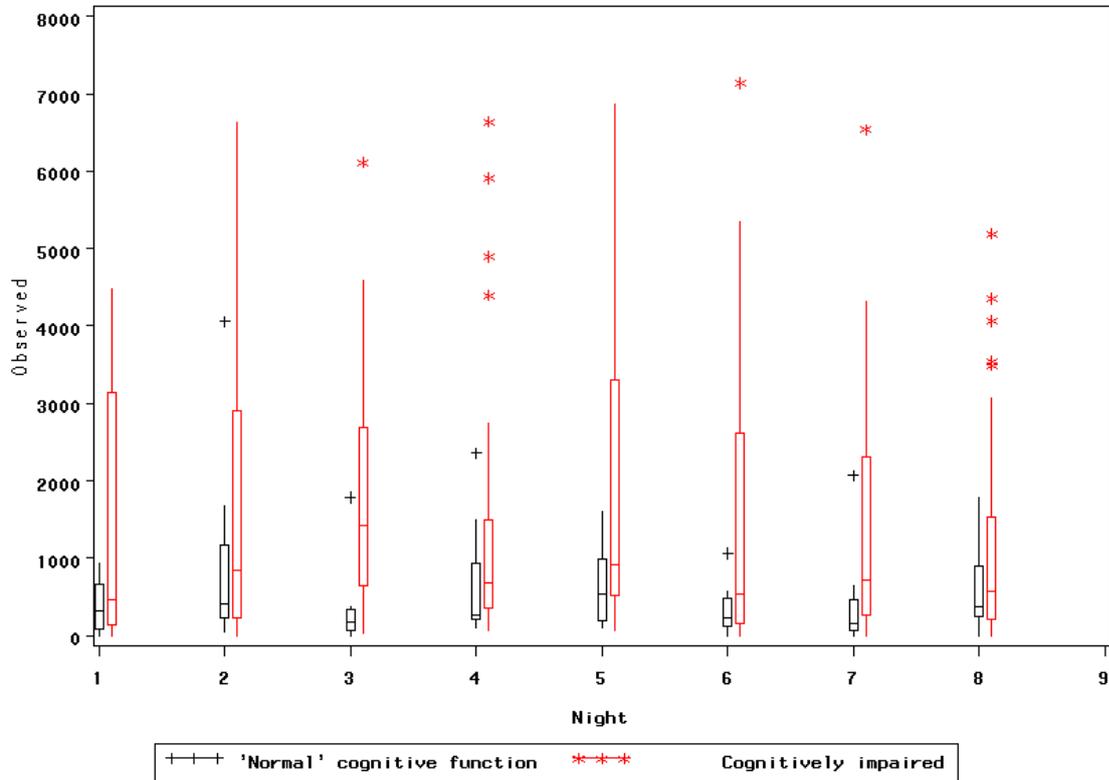
In addition, all these variables (not outcome) were entered in a multiple logistic regression model to estimate the probability of having to not having the missing depressed variable explained by these variables using stepwise backward elimination. Again, none of the variables were retained in the final model. One patient who did not have any covariate was excluded in this analysis.



**Figure 4.5 shows boxplots of observed nocturnal activity by different groups for the cross-sectional analysis**

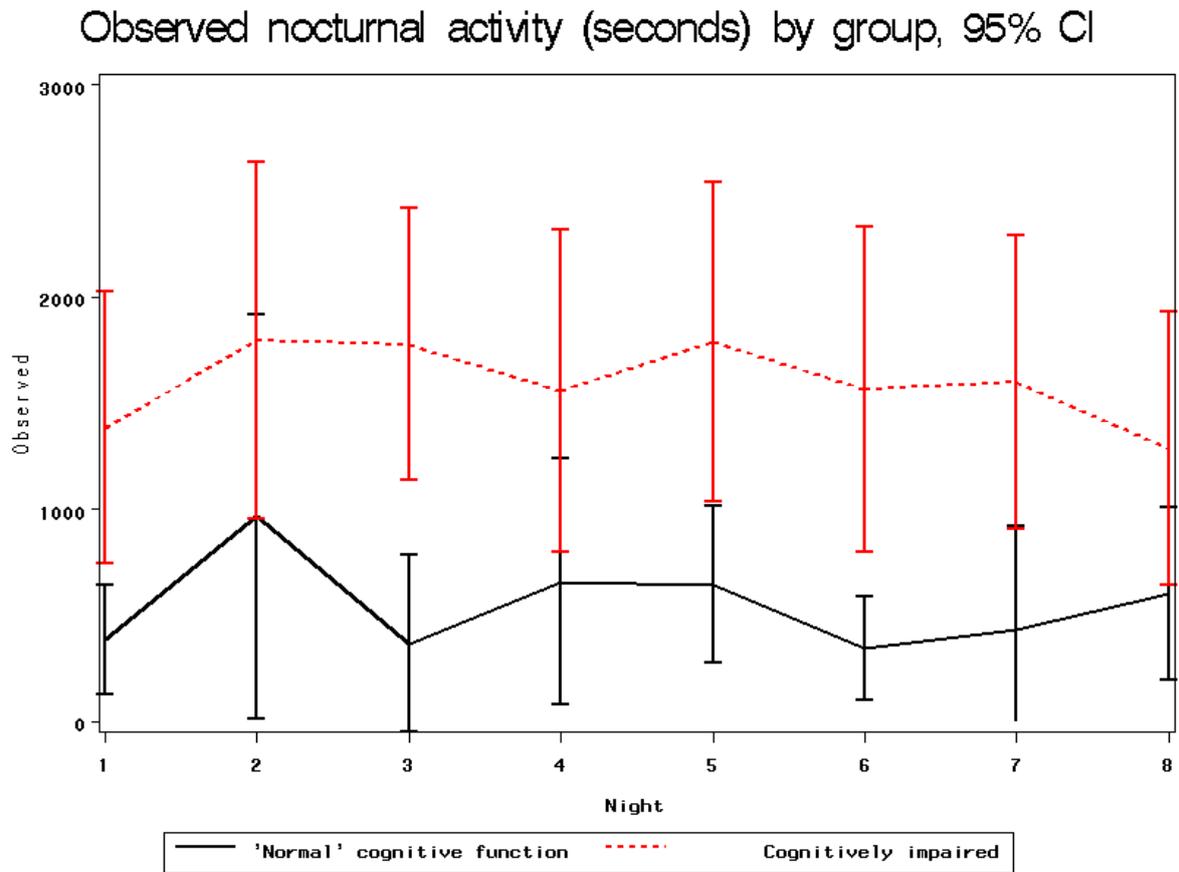
- N = variable (*i.e.*, 33 to 45 according to missing covariates).

## Boxplots of observed nocturnal activity (seconds) by group

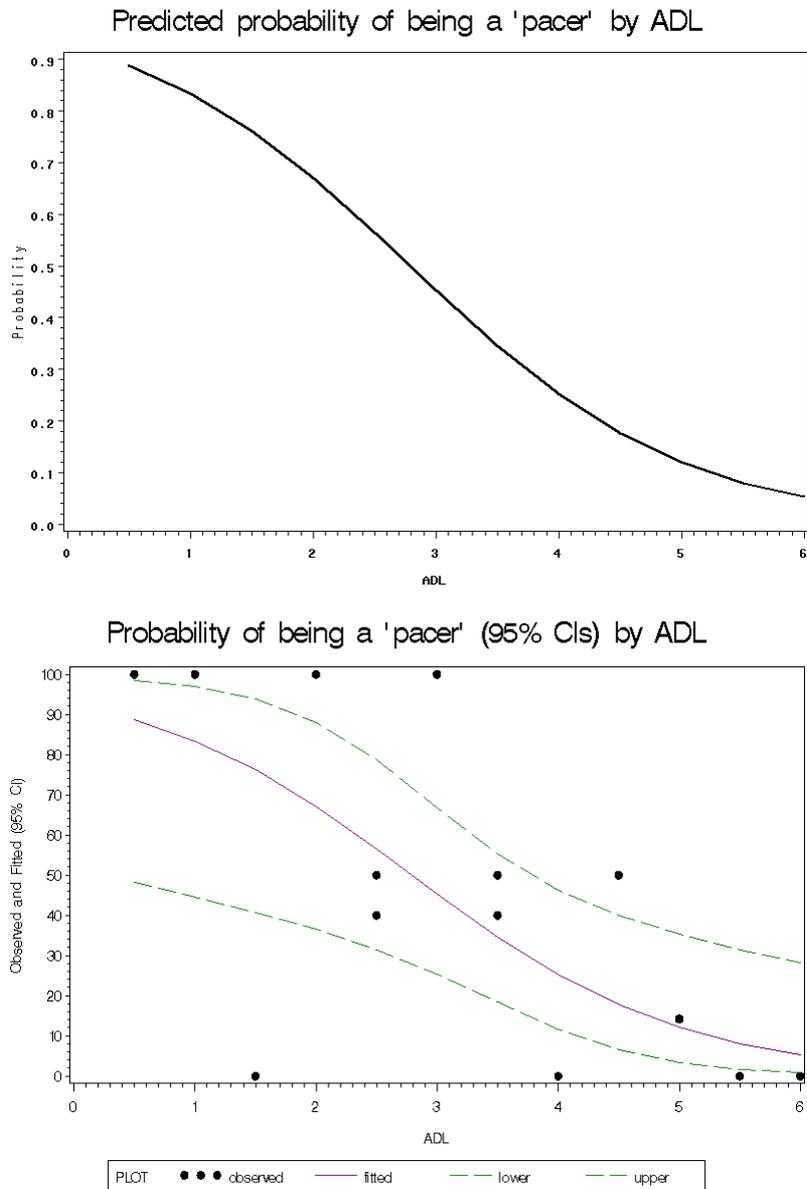


*Figure 4.6 shows the boxplots of observed nocturnal activity by cognitive status over 8 nights for the longitudinal analysis*

- Distribution appears to be heavily right skewed in the cognitively impaired group.



*Figure 4.7 shows the average (95% CI) observed evolution by cognitive status for the longitudinal analysis*



**Figure 4.8 shows the predicted probability of being a 'pacer' to a 'non-pacer' by ADL for the cross-sectional analysis**

- A logistic regression model was fitted based on the results of finite mixture analysis to identify the determinant of being a 'pacer' (= high mean nocturnal activity, >1700 seconds) to a 'non-pacer' (low mean nocturnal activity) in the given sample population of elderly inpatients with varying levels of cognitive function loss. The fit statistics were good, except 1 serious outlier.

- In the right figure, a black dot may be derived from more than one individual having same probabilities.
- A backward elimination procedure was applied with variables: cognitive status, depressed status, interaction 'cognitive X depressed' status, ADL, *prosthesis*, *antidepressants*, *neuroleptics*, *hypnotics*, *continence* and *weight*. Only ADL was retained in the final model showing an inverse relationship with the predicted probability of being a "pacer"; OR = 0.4 (0.2-0.8, 95% CI; p <0.01). This translates to odds of being a "pacer" decreases by 0.4 times with each unit rise in ADL score.

## **4.6 Discussion**

### **4.6.1 Reliability of our data**

Nocturnal actigraphy through PIRS has proved to be a reliable way to follow up hospitalized patients. First of all it is a non intrusive method and this aloud to get data that are not biased through the presence of a worn device. Researchers that use worn devices tight to the wrist assure that persons can get used to it. But we cannot be sure at 100% at which moment the device might be the cause of activity especially in patients with dementia, only in those cases when patients are seen trying to get rid of it. Authors say that new devices have a security disposal to avoid that patients with dementia or who might be agitated can take it off.

Therefore we can be sure that discrete PIRS that are on the walls cannot disturb patients. In fact this issue was already studied in a previous experiment (Banerjee, 2003).

### **4.6.2 Interpretation of the results**

As mentioned before, for the analysis of data some variables that probably readers would want to find on it were not used, like the NPI score. The reason was that from the first pool of patients that was analyzed it was seen that this variable did not have an impact.

The NPI score has been used to validate behavior modifications in different type of interventions, mainly using clinical outcomes (Mossele, 2008). But in the case of actigraphy using GARDIEN® activity can be differentiated mainly in three aspects; total activity in time, the place where it occurred and according to an algorithm, the type of activity is tabulated either as agitation in bed or out of it and displacements. Agitation per se would be the only matched item with the NPI itself.

For the purpose of this study we wanted mainly to study the correlation between activity and the level of autonomy, the presence or absence of cognitive problems and depressive symptoms. Professionals working with patients are aware that these variables are usually concomitant and that precisely this can be a problem in deciding what we want or should treat.

On one hand geriatricians try to avoid poly-medication, not because of the number of drugs but to avoid interactions and adverse effects. And on the other hand we are obligated to treat this patients who have mainly BPSD and especially when they are exacerbated during the night.

Having said so, here we discuss our findings.

Dementia and Nocturnal activity: As shown in different tables and figures either for the cross sectional as for the longitudinal analysis, patients with cognitive problems had in general a higher mean nocturnal activity. These findings are consistent to what it has been reported by other authors. In the study from Volicer, subjects suffering from DAT had lower daytime activity and higher nocturnal activity and lower inter daily stability and later activity acrophase compared to persons without dementia (Volicer, 2001). The same results were found by Harper, but their studies were mainly dedicated to sleep disturbances. Boeve in the Mayo Clinic did even categorized sleep problems in patients with dementia in four groups according to symptoms: insomnia, hypersomnia, excessive nocturnal motor activity, and hallucinations or behavioral problems. We have shown in the previous work that all our patients with dementia had a marked elevated nocturnal activity (Boeve, 2002).

Paavilainen did study activity rhythm in patients with and without dementia but in a nursing home and found the same results, but in these studies actigraphy was done with a worn accelerometer. (Paavilainen, 2005). We did not differentiate between the types of dementia, because the number of patients was small. We had only one patient with fronto temporal dementia. But for example Anderson using wearable actigraphs with 13 patients with fronto temporal dementia and comparing data to matched controls from a pool with DAT showed that in non institutionalized patients with FTD early sleep disturbance may help differentiate between FTD and DAT. (Anderson, 2009) Once again here the main outcomes were focused on sleep pattern alterations. Nocturnal activity is part of them but still not adapted to sleep research particularities. In the study from Paavilainen, they had a comparable population of patients to our study. Even if their patients were in a nursing home, this can be partially comparable to our patients because we are a structure for half long term care hospitalizations. She studied 19 non demented and 23 demented persons, and use as outcome variables the same we did, but with different scales. Cognitive status through the MMSE, but they define a normal subject when the MMSE score  $\geq 20$  and a CDR  $\leq 0.5$ . The presence of depressive symptoms was accorded using the GDS 5 score and for the level of autonomy she used the Barthel Index.

In her study the mean MMSE in the dementia group was  $11,6 \pm 5.6$  and in our group it was  $14 \pm 5$ . The cutoff point using the MMSE was 24 like in most studies. But we can add that for patients with the diagnosis of dementia, this was done according to the standards in France for our population studied.

When looking at the level of autonomy in the group studied by Paavilainen, the Barthel index for patients without dementia was  $82.1 \pm 24.1$  compared to  $65.0 \pm 19.4$  in the group with dementia

( $p= 0.001$ ), meaning that there is a concordance with our findings, regarding the autonomy level. This means the more impairment the more dependent for autonomy.

When we analyze the probability of being a pacer we used nocturnal activity as outcome, this was also possible because less than 10% of this activity was due to agitation in bed. Some authors classify the "wandering behavior" as a group of motor disturbances that imply agitation and displacements; as we did for this analysis. What is different from what was seen in the REAL cohort is the interaction between the level of ADL and wandering. This is probably because in our study the OR for being a pacer, even if low, augments by the loss of ADL points. In the REAL cohort the ADL was even slightly higher in wanderers compared to controls (Rolland, 2007). We can explain this because our patients had as inclusion criteria to be able to walk freely. In the REAL cohort although being in home subjects, we do not know their level of capacity for displacements, only a total ADL score.

Depression is a factor that can disrupt the sleep/wake pattern in old age (Bliwise, 1993). As it was expressed in the first chapter, sometimes it is difficult to differentiate if it is depression the source of a disrupted sleep or vice versa. When it is the case of patients with dementia, then it is probably more difficult. Then first of all we need to look after depression in these patients, which is not routine. In fact results from the REAL cohort study, involving community dwelling elderly in France, show that unfortunately only 60% of patients with DAT and depressive symptoms are treated (Arbus, 2010).

One of the limitations of our study is that we did not use the Cornell Scale for patients with dementia. But for the persons we did get the GDS it was reliable. For some patients there was even a note from a psychologist confirming the presence of depression based on a clinical interview and others were even treated for it as it was shown in table 4.1. So from our pool of 25 patients with cognitive problems, 10 were treated with anti depressants. For instance in a study done with 87 women with dementia followed by wrist actigraphy, which had as outcome to investigate the association between actigraphic estimates of sleep-wake rhythm and a range of functional domains that contribute to well being the comparable results are the following. The authors used the Cornell Scale to study mood disorders in their population and found a higher number and severity of depressive symptoms was associated with more fragmented, less stable rest activity rhythm and higher nocturnal activity. These results differ from our finding (Carvalho-Bos, 2007). When looking to the figures we can see that depression is a variable that has an important impact on total nocturnal activity. It was consistent through all analysis and the main outputs are that a) depression does augment nocturnal total activity in normal patients, which is in accordance to what it has been

said by other authors and b) depression has an opposite effect on patients with cognitive impairment, this means that it diminishes total nocturnal activity for this group.

This could be rather paradoxal, because we would assume that depression should also augment probably anxiety and sleep fragmentation in these patients, but there must be another more important aspect of depression that deems this effect and tends to calm down patients during the night. One possible explanation could be the appearance of apathy. This symptom can also be part of the depression in some cases but it can also be part of dementia. We did not make a difference according to the level of depressive symptoms, then we know that the GDS gives just an estimation, We believe that these results open the question to analyze in a further project the effect of depression in dementia on nocturnal activity, but using a more adapted screening tool for depression in this population and also differentiating the different types of dementia.

If it is the case that apathy would be contributing to diminishing total nocturnal activity, then this would mainly happen in those patients probable with more severe dementia, since it has been proved that it usually appears at later stages (Lövheim, 2008). But we did not consider in this analysis to separate the patients with dementia in subgroups according to the level of cognitive impairment or etiology, basically because we would need more subjects to conclude something.

For the group without cognitive problems, one possible explanation for the augmentation of nocturnal activity could be the following. It must also be taken into account that even if we had a period of 8 nights, some of the patients could have been also suffering from delirium. This was better exemplified by the patient who stayed three months, (chapter 5) then the fluctuation in the intensity of behavioral problems and nocturnal activity was evident during the first three weeks of his stay. In fact we did not use a score to evaluate confusion, like the CAM, which can be a limitation for our study, because it is also known that depressive symptoms can be a risk factor for delirium and the presence of delirium would explain an exacerbation of nocturnal activity. This could be a point to evaluate further in future studies. For instance using actigraphy a different classification based on activity patters was already proposed in 1998 by Hohma. He examined the activity patterns in 13 demented patients with delirium who wore actigraphs for more than 10 days. They were classified into four types: type A, nocturnal delirium type; type B, wandering type; type C, hypobulia type; and type D, lying down type. The day to day activity variation was most prominent in type A and seemingly the least in type B. The dominant period of activity rhythm was nearly 24 h in all cases. Additional 12-h period was observed in type C. he did conclude that could be useful in making therapeutic decisions regarding demented patients with delirium (Hohma, 1998). So this shows that multiple phenomena can influence activity in patients with dementia but that still a superimposed delirium can be identified by actigraphy. But to do so the "normal" pattern

without delirium should be known to be sure that we have a superimposed effect or we need longer periods of registration to be able to differentiate a stabilization of the activity. This is the case of one of our patients (Chapter 5)

It is important to say that usually depression tends to augment sleep fragmentation, but with environmental activity this phenomenon might be more difficult to detect. This could be possible if we make a detailed analysis for each night period, but this can be really time consuming and was out of the scope of the study. For this purpose wearable sensors might be more adapted and accurate.

Again according to the study of Carvalho mentioned above, done with a group of demented women, there is not an explanation for poor circadian patterning of periods of rest- activity. This can probably be because the rest-activity rhythm has a strong exogenous component masked by environmental demands on behavior.

Evidence exists since more a decade proving that the level and the distribution of activity provide input to the circadian timing system, meaning that even moderate activity per se may phase delay the circadian rhythm (Buxton, 1997).

In this study we took only total nocturnal activity as outcome, because these results are easy to read and interpret by the clinician and we want to offer a tool to better analyze nocturnal behavior in daily life for patients hospitalized in geriatric wards or nursing homes.

The typical pattern of nursing home residents with dementia involves sleep that is extremely fragmented throughout the day and night. In fact, on average, these patients are rarely asleep for a full hour and rarely awake for a full hour (ie, not a single hour in a 24-hour day is spent fully awake or fully asleep) (Ancoli, 2005). The time periods of greatest alertness are during meals, but some residents fall asleep even at those times. In one study, patients with severe dementia slept about 58% of the night, compared to those with mild-to-moderate dementia who slept about 45% of the night. In addition, those with severe dementia napped during 29% of the day compared to 15% for those with mild-to-moderate dementia. Thus, both groups spent much of the day and night in fragmented sleep (and fragmented wake) (Ancoli, 1995).

So in general our results are consistent with those from other authors concerning the level of activity when comparing persons with and without cognitive problems. But when we look at the level of autonomy, we find the following. We did formulate the hypothesis that the level of autonomy measured by ADLS should be related to the nocturnal activity level, and this variable is known to be

related to cognitive level. In our group of patients those with cognitive problems had a mean ADL score of 3.5 compared to 4.7 for the group without cognitive problems. So we could see the participation of this variable mainly in fig 4.5. This is not something new, but our idea is to use this information from the other side. Maybe if we measure nocturnal activity through actigraphy in this parameter, this can help us get a better idea of the possible performance.

In fact sensors are located in different places of the room and so we can be sure that the person did go the bathroom or that he is capable of walking in the room doing the transfers from bed to bathroom, to the door and so on. So actigraphy data can be a reliable way to validate some ADLS, specially for patients who live alone and for whom we have doubts, because sometimes this type of patients are sleepy and not really active during the day when evaluated by medical staff.

Another important issue is that these results can help better understand which aspects can be a risk to develop a wandering behavior. Understanding by wandering those persons with high nocturnal activity, since this means that the person was turning around in his room during that time.

So having said so, we can see from figure 4.9 that in this pool of patients having a better score in ADLS and a lower score in MMSE are related to being a wanderer.

This was probably influenced by the fact that in our population also the most demented patients had a lower ADL score.

## **4.7 Conclusion**

The main conclusions from a statistical point of view in this study are:

- Highly right skewed distribution of the nocturnal activity; mean nocturnal activity proportional to standard deviation.
- Significant over dispersion is present in the outcome. Due to this nature of the data, models with Poisson distribution fitted poorly. Notwithstanding, gamma or negative binomial distribution yielded good fit and provided similar parameter estimates in both cross-sectional and longitudinal data.
- No effect of time or interaction between time and another covariate in the short-term evolution (1 week) of the patients.

- Although there is correlation among the repeated measures, but it is estimated to be constant across different time points, *i.e.*, the compound symmetry or exchangeability condition.
- ADL, cognitive and depressed status being the significant predictors of nocturnal activity. Interaction between cognitive and depressed status.
- ADL, not cognitive or depressed status, is the lone significant predictor (among measured variables) on the probability of being a “pacer”.

In general:

Measuring total nocturnal activity by PIRS might be a valid outcome to use in further studies regarding depressive symptoms and dementia, functional status and dementia and probably other quality of life factors, like total sleep time.

## RESUME DU CHAPITRE 5.

Les troubles du comportement nocturne chez les déments sont fréquents, surtout la nuit avec l'inversion du cycle veille sommeil. Le repérage de ces troubles par une meilleure connaissance de l'activité nocturne peut aider à gérer ces patients et éviter l'abus de psychotropes.

Nous présentons le cas d'un homme de 79 ans suivi par actimétrie environnementale en utilisant le système GARDIEN® qui comporte 9 capteurs infra rouges dans une chambre d'hospitalisation. M. B connu pour une démence mixte et un diabète insulino-requérant, était hospitalisé pour agitation. Sur 75 nuits, la moyenne d'activité entre minuit et 6 h était de 17.9 minutes et entre 21 et 6h de 35 minutes ce qui est élevé en comparaison au groupe de référence. Le patient a présenté des pics d'hyperactivité nocturne a plusieurs reprises qui ne correspondent pas toujours aux rapports des soignants. Le système apparait capable d'identifier une hyperactivité en lien avec une altération métabolique (hyper ou hypoglycémie). L'actimétrie révèle cependant un pattern de stabilisation comportemental chez ce patient dément dont le MMSE au départ de 11/30 est passé à 21/30. En conclusion l'actimétrie peut être utile pour la surveillance des troubles du comportement surtout nocturne et révéler des pathologies intercurrentes chez le patient dément.

## **CHAPTER 5. ENVIRONMENTAL ACTIGRAPHY IN THE HOSPITAL AN ITS CLINICAL USE**

### **ACUTE CONFUSIONAL STATE AND BPSD IN A PATIENT WITH MIXED DEMENTIA. FOLLOW UP BY ACTIGRAPHY THROUGH PASSIVE INFRA RED SENSORS . A CASE REPORT.**

#### **5.1 Introduction**

Acute confusional state is one of the main reasons of hospitalisations in emergency rooms and in geriatric facilities. In emergency departments up to 40 % of patients over 70 years present mental status alterations and around 25% have delirium when evaluated by a geriatric team (Laniece, 2009). This rate is even higher when patients are referred from geriatric facilities (64%). Approximately 15 - 60 % of elderly patients experience a delirium prior to or during a hospitalization but the diagnosis is missed in up to 70% of cases. Delirium is associated with poor outcomes such as prolonged hospitalization, functional decline, and increased use of chemical and physical restraints. Delirium increases the risk of nursing home admission. Risk factors for delirium include older age, prior cognitive impairment, presence of infection, severe illness or multiple co-morbidities, dehydration, psychotropic medication use, alcoholism, vision impairment and fractures. (Inouye, 1990)

Mostly emergency departments are not adapted to treat this type of patients and the use of physical and chemical restrains is unfortunately common. In general when the underlying cause has been found and treated, mental alterations disappear or diminished; in the later case is mainly because cognitive impairment already existed. Then we face Behavioural and Psychological Symptoms of Dementia (BPSD). BPSD refers to a group of non cognitive symptoms and behaviours that occur in people with moderate to severe dementia (Finkel, 1996). Some of them are more common during the evening depending from light exposure like the sundowning syndrome. The American Sleep Disorders Association considers sundowning to include "the sleep disturbance that is characterised by nocturnal wandering and confusion". In fact sundowning is defined as a worsening of disruptive behaviour in the late afternoon or evening among dementia patients (Sharer, 2008). The role of

circadian rhythm alterations is also a contributing factor to sundowning and other nocturnal disorders in dementia (Volicer, 2001). Not all authors agree with the term "sundowning" and for example Cohen Mainsfield J proposed to no longer use this term, since in his study he could not evidence a higher prevalence of agitation in the afternoon. He examined 172 subjects in 12 nursing homes (Cohen- Mainsfield J, 2007).

But afternoon agitation can be as high as 66% among patients living at home being this a major problem for caregivers and relatives, and a risk factor for caregiver's burnout and institutionalisation. External or environmental factors like less illumination can be part of the aetiology which are exacerbated by visual problems common in this population. Agitation is also very common. Already in 1991 Cohen Mansfield reported the different ways of studying this problem and evoked also technology (Cohen-Mainsfield, 1989 and 1997). Wandering can be defined as a tendency to move about and frequent and/ or unpredictable pacing with no discernible goal. (Trubel, 2008) Its prevalence in France is around 12% in community dwelling patients with Alzheimer's disease (Robin, 2001; Vellas, 2003 ). Since it seems more a qualitative variable that can be confounded or merge with agitation, some authors have tried to quantify it by using a pedometer. So wanderers defined by pedometer correspond to clinically identified wanderers because the scores of the "wandering" category were positively correlated to total daily steps. And when analysing this feature it is more common in moderate stages of the disease (Robin, 2001).

REM sleep behaviour Disorders (RBD) is a type of parasomnia that is typical from elderly persons and has been related to alpha synucleinopathies. It is characterized by nocturnal complex motor activity. Some studies have related its presence to the future development of Parkinson Disease or Dementia of Lewy Bodies Type.

To better understand these symptoms that cannot be surveyed continuously neither at home nor in emergency departments or normal geriatric facilities, actigraphy has been proposed as a method to follow up patients presenting these behavioural problems (Ancoli, 1995).

Actigraphy using a bracelet has been widely used and has proved to be a good tool to monitor activity for patients with behavioural or sleep problems. The inconveniences are the possibility of taking off the device and get injured. Therefore another proposal is actigraphy through environmental sensors. Passive Infrared Sensors have also shown to be useful in monitoring activity, especially during the night since they do not bother the patient at all.

Quantifying activity can help to understand how patients function during the night time, to have a more objective follow up of the efficiency or side effects of a treatment.

We present here the case of a patient who resumes several behavioural problems and its typical evolution, surveyed by environmental actigraphy using Passive Infra Red Sensors (PIRS).

## **5.2 Objective**

The aim of this case report was to analyse the nocturnal activity pattern of the automated actigraphic reports using the system GARDIEN ® and compare it to the information gathered from the nurse staff records.

## **5.3 Case**

Mr B is a 79 years old man who was admitted to the geriatric department. He is a former labour worker from Italian origin, living in France since his early adulthood and speaks both languages fluently. He has been married for over 40 years and has five children. He has several medical problems: Insuline Dependent Diabetes Mellitus (IDDM), antecedent of gastric ulcer, biliary lithiasis, peri- renal abscess and an open prostatectomy.

He was first hospitalised for a metabolic problem secondary to misuse of insulin early in February, 2009. He was discharged to his home where he used to live with his wife, but then the patient started neglecting himself after his wife departure. She could no longer support to live with him, because he had become aggressive verbally and physically to her and others. According to his son, this problem started some months ago, with a paranoid attitude, trying to hide himself and things and being suspicious of everybody. At the first hospitalisation he presented an acute confusional state secondary to hyperglycemia (Haemoglobin A1C at 8.7). A CT scan did show only periventricular leuco araiosis. The Mini Mental Status Exam (MMSE) was at 11/30 and the Instrumental Activity of Daily Living (IADL) was at 5/8. He was sent home with an important number of home aids, a nurse coming daily for glycemic control and medications survey. Six weeks later he was sent again to the hospital by his general physician in response to the family request of hospitalisation, because the situation at home was "catastrophic". He became paranoiac and violent and avoided the contact with the rest of his relatives. He neglected himself and also put his own life in danger, by "working" with the electric spots and doing and undoing little handwork's. The patient was hospitalised against his will in agreement between the family and the doctors.

At his arrival Mr B was very agitated trying to find the exit. He was hospitalised in a single room in which we had install the GARDIEN ® system. The patient was awake and agitated almost all the night. A positive urinary test was found and antibiotic treatment started. During the second day in

the morning he was calm and tired. Then he was wandering on the unit and at the afternoon started being agitated. So risperidone was introduced. During the night he woke up and was again wandering and shouting after his wallet. He accepted resting in his room but during the night he was "working" as he said and broke the light, the hand towel handle and a chair. In the morning a glycemic control revealed hypoglycaemia and insulin was adjusted. The next day he was calm and again agitation started during the evening and over the night and he was treated with haloperidol. The next day he presented the same behaviour with an inversion of the awake/sleep cycle and nocturnal agitation controlled with haloperidol intra muscular injection. The subsequent two weeks we found a similar pattern of behaviour according to the nurse records but less active. His glycemia was really difficult to control with several hyperglycaemia picks always related to agitation and nocturnal behavioral problems.

The patient stayed manageable for three weeks. On day 23, he was evaluated by a psychologist who concluded that it was probably a vascular dementia. The MMSE was at 21/30 the clock drawing test at 20/30. Then the patient was cooperative, well oriented but he had severe apraxias and visio constructive problems and was difficult to evaluate due to his perseverance in talking in Italian (his mother tongue language). Then he had some episodes of craving for sweets that again cause a metabolic decontrol with hyperglycaemia causing slight episodes of agitation, disorientation and confusion, easy controlled with lorazepam while a glycemic control was achieved. Over several weeks, Antipsychotics, were used at least 5 times (haloperidol IM and twice loxapine) when he was very aggressive and also different sedative drugs were tried (lorazepam, meprobamate, zopiclone). When rivastigmine was introduced after one week he was more stable and needed less hypnotics. Psychotropics were mostly prescribed by doctors on call as unique doses during the night period while he was agitated.

Finally, he was discharged to a psychogeriatric unit after almost 4 months of hospitalisation with the diagnosis of probable mixed dementia.

## **5.4 Methods**

We compare behavior noted in the nurse records to the automated reports given by the actigraphic system. The patient was in a room equipped with a system that uses 8 Passive Infra Red Sensors (PIRS). This system called GARDIEN® has been validated in previous studies.( Banerjee,2003). The sensors are located as shown in fig 1. This arrangement permits to have a good overview of all significant movements and displacements in the room, in the toilet and detects if the patient leaves

the room. The system gives an automated report signaling number of displacements in the bedroom, in the toilet, agitation in bed (see fig below).

# AMBULATORY ACTIGRAPHY

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Note: Agitations in bed of < 5 movements are not registered. Displacements are separated by at least 30 seconds still time.

	Daytime		Nighttime
	0		1
<u>Displacement to toilets</u>			
Duration (sec)	0		252
	11	<u>1</u>	0
<u>Agitations in bed</u>			
Duration (sec)	557		0
	79	<u>6</u>	41
<u>Displacements</u>			<u>1</u>
Duration (sec)	10581		3705

Underlined, the number of agitations > 2 minutes and the number of displacements > 5 minutes.

**Fig 5.1 GARDIEN ® Automated report for the health personnel**

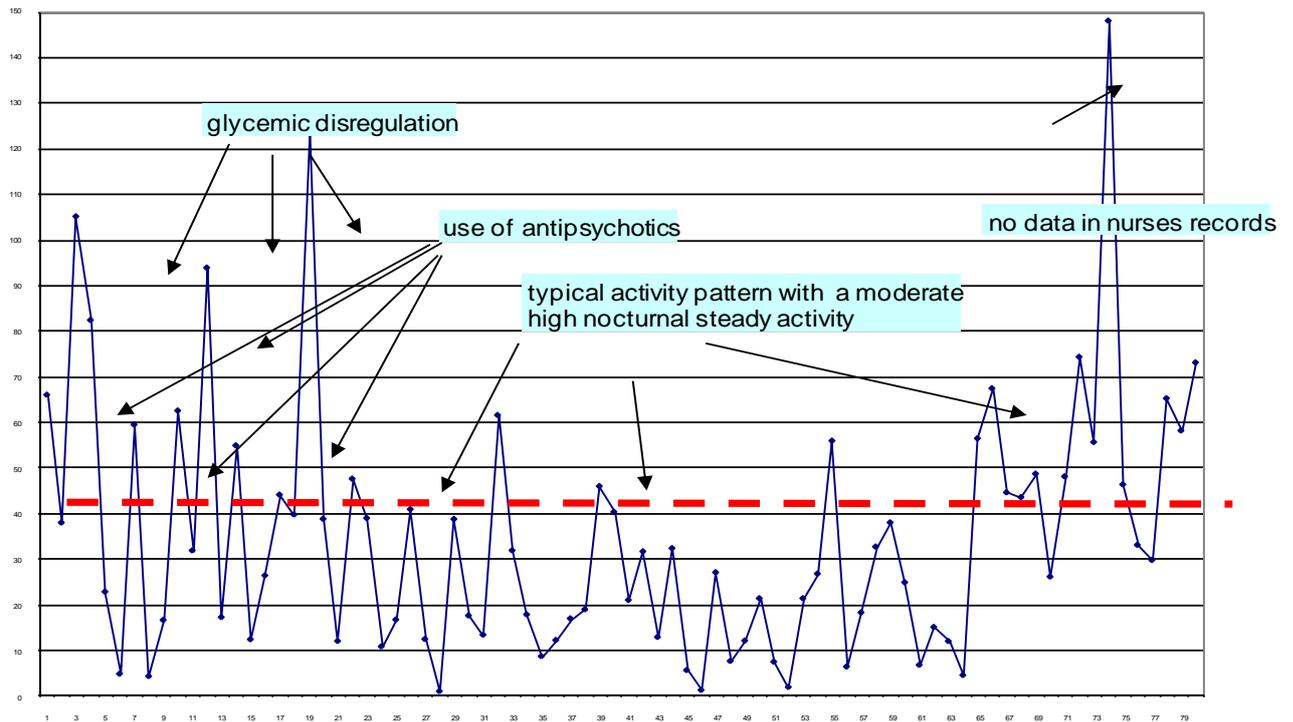
This automated report can be useful for the health personnel in order to better follow up these patients, especially during the night time. Therefore we are comparing here the activity reported by nurses and that given by the system.

Only nocturnal actigraphic activity (from midnight until 5:59 hr) was compared to the information described in the nurse records. Nocturnal staff does in average three rounds, one at midnight, another around at 4 am and then at 6 am and goes only see patients that ask for help or in case of agitation. The agreement between the nurse's reports and the actigraphic data was done, as follows. We looked in the reports for keywords describing the behaviour during the night like: calm night, agitation, aggressive behaviour, wandering. If the staff did not register anything, then it was assumed that the night was calm. Staff was aware of the GARDIEN® system but not that we were comparing records to avoid biases (that they would take special care about this patient). Then we describe the nocturnal activity pattern compared to the clinical evolution.

## **5.5 Results**

The patient was hospitalised for 124 days, but we got actigraphic records from 79 nights (63.9%). The reason for losing the records, were mainly due to interference and unplugging by error because the computer had to be installed in the nurses room where many persons had access and during that period there were several blackouts while the installation of the air conditioning in the ward.

The patient had a relative a high activity over the whole period, with a mean activity of 47.94 Mins + 27.10 SD. Then he presented some picks of high activity that we can identify. While comparing them to the medical record, he was very aggressive and active during the night on day 3 and 4 and on day 5 when a low DTX 3.8 mmol was found; few weeks later again he was very active during 2 consecutive nights we found that he had 48 hrs before a DTX with 12.8 mmol. Although the DTX was corrected he remained agitated and was treated with haloperidol. He was down for one day and then he rebound with hyperactivity. Episodes similar to this happened again. The agreement between the written report done by the staff and the actigraphic one, was not accurate for 24 (30.37%) nights , where staff did not record any activity assuming he was calm and GARDIEN showed an activity over 1000 seconds which is almost the mean  $\pm 2SD$ .



*Fig. 5.2 mean nocturnal activity in minutes over 79 nights*

## **5.6 Discussion**

We wanted to present this case for several reasons. This can be an example of the typical case to which most geriatricians have been confronted. The patient without a known history of dementia or cognitive problems, or just some vague personality features traced in a medical record, who arrives to the emergency department because of agitation and impossibility to be managed at home. Afterwards this situation needs weeks to be controlled and the diagnosis of some probable type of dementia is evoked and the patient can be followed up correctly. This typical "parcours", implicates on one hand a failure in the health system to detect on time patients with cognitive impairment,

secondly the costs related to a long hospitalisation and third the difficulties in trying to control the behavioural problems. The two first points are beyond the scope of this article, so our discussion will be based on the use of actigraphy to monitor the activity as a marker of behaviour/ agitation.

Actigraphy mainly done by the wearable accelerometers in form of bracelets or collar have shown their efficacy in studying activity, mainly during the night and also for demented patients and agitation (Mahlberg, 2007). The problem that can sometimes emerge is that the device can bother the patient and even stimulate him to take it off to avoid this, a security can be adapted. This type of actigraphs are very efficient in detecting low or fine movements, which for certain types of studies could overestimate activity, for example patients who move much during sleep.

In this case we exemplified the discordance that can exist between the appreciation from nocturnal staff and the real activity during the night. This can be due to "bias of getting used" this means that health personnel do not record the problems because they are so frequent that they "get used" to them and take them as "normal" for the patient (Hermann, 2008).

As seen over the total recorded period the patient presented some rebound in hyperactivity, mostly explained through medical or metabolic dysregulation but probably the use of different types of psychotropic drugs might have influenced. The decision of the physician on prescribing this type of medication is strongly influenced from nurse's reports, so probably it should be important to use also the actigraphic records for this purpose. Then in this case we could evidence that nocturnal hyperactivity did occur before daily aggressiveness in three occasions. So this fact could have alert the staff in advance and probably encourage them to look after a possible underlying (metabolic) cause that was altered (records were not provided ). This case also exemplifies that glycaemic control is very important and that for this patient this problem was the main source of an altered behaviour during the first weeks of hospitalization. Probably an important factor contributing to the difficulty to manage the glycaemia was the inappropriate use of different antipsychotics. It has been proved that this type of medication might increase glycaemia (Lipscombe, 2009). Physicians prescribing these medications have to be aware of this adverse event and adapt the whole treatment, otherwise a vicious circle may appear more antipsychotics, more metabolic disorders then more behavioural problems so this case can be a good reminder that a close glycaemia control should be done. It can then be proposed that the patient presented an acute confusional state in an intermittent way and once he recovered when his MMSE was at 21/30 then he presented the typical BPSD. In fact we can also evidence that the patient presented during the first three weeks a delirium pattern, since a) he had the typical fluctuation of behaviour mainly expressed by agitation and sleep alterations through high irregular nocturnal activity and b) because he recover more than 5 points in the MMSE. So in

some manner actigraphy through PIRS can also be a valid outcome measure for cases with doubt of acute confusional state.

Although most authors agree that BPSD appear at later stages of dementia, through the actigraphic data from the patient we could have an idea of his nocturnal activity pattern that remain rather stable during the last weeks but that correspond to that of patients with moderate dementia. So here actigraphy could help classify the patient in a moderate group even if his MMSE was 21 when he was discharged. Comparing his pattern to previous ones reported by our group, we could classify him in the group of nocturnal moderate active

The importance is that this patient came from home and was lucky to find a place in a psychogeriatric ward. Otherwise, if he would have returned home even with home aids during the night it would have been a chaos. As Lalor explains the characteristics of the behaviour or symptoms together with the frequency, severity and impact on the patient and caregiver must be identified before formulating a tailored and targeted plan of action which is likely to involve pharmacological and non-pharmacological Interventions (Lalor, 2002).

This case also shows the need to build psychogeriatric intensive care units (PICA) for older adults. Then our patient was in a normal geriatric sector and his behavioural problems did annoy other patients and the staff. This was one more reason for the excessive use of anti psychotic drugs. These type of Units started in the USA over 30 years, they are conceived for patients compulsorily detained usually in secure conditions, who are in an acutely disturbed phase of a mental disorder. And we propose that adding a system like GARDIEN in some rooms would help to better follow up this type of patients with aggressiveness and agitation. It is a cost effective investment that does not bother the patient, is not intrusive. It is ethically correct since information can be encrypted and only delivered to the chosen health personnel.

In this particular case, since the patient "disturbed", this issue encourage the decision of chemical contention. Probably if the patient would have been in a psychogeriatric unit and once that a pattern of activity was recognized then another approach would have help everybody to breathe. Then the patient would have been respected in his hyperactivity and the overuse of psychotropic drugs would probably have been avoided. The opposite can happen, patients that seem to be calm because they seem quite but in fact can be very active during the night. An actigram can alert staff of an underlying problem, or after a judicious longer period of surveillance then the usual or individual pattern of activity can be identify, this will help understand how a particular patient functions during the night. If the staff is informed then the nocturnal activity pattern of a patient with dementia can be respect and this would avoid to force him to sleep over the whole night using sedatives. We believe that this point is of capital importance and could help avoid iatrogenic procedures. Maybe

this could be a good objective to measure in future studies and also help to explain more objectively to health personnel how a patient with dementia functions during the night.

## **5.7 Conclusion**

Using technology to better handle patients is a fact. We propose GARDIEN® as a good tool to quantify nocturnal activity in order to help night staff getting a better register of nocturnal behaviour. This would help to a better understanding of patient's behaviour and to programme a more realistic follow up procedure.

## RESUME DU CHAPITRE 6

L'évaluation de l'activité nocturne est importante pour le suivi des patients déments. Cependant le personnel de nuit est souvent insuffisant et les évaluations du comportement nocturne peuvent être incomplètes ou non ciblées. Nous proposons une échelle semi qualitative, qui a été développée et validée avec l'actimétrie par capteurs infra rouges. Cette échelle simple a été proposée au personnel de nuit et comparé avec les résultats obtenus par deux experts qui l'ont remplis en utilisant les données actimétriques automatiques, issues du système. Vingt-sept patients d'âge moyens de 82 ans, dont 19 avec troubles cognitifs avec un MMSE moyen de 13/30 ont été évalués. Un consentement écrit a été donné par le patient ou son représentant légal. L'échelle a 4 niveaux de sévérité, de «0» pas de mouvement observé à «3» se lever du lit plus de 5 fois par nuit. Nous avons enregistré 352 nuits. Pour le groupe avec troubles cognitifs sur 295 nuits d'observation, la kappa de concordance était de 0.45 (95%CI 0.38-0.52) et de 0.27 (95%CI 0.08-0.46) pour le groupe control (57 nuits). Cette échelle peut être utile pour quantifier d'une façon plus objective le comportement nocturne, spécifiquement chez le dément.

## **CHAPTER 6. USE OF ENVIRONMENTAL ACTIGRAPHY TO VALIDATE A SEMIQUANTITATIVE SCALE TO EVALUTE NOCTURNAL ACTIVITY**

### **6.1 Introduction**

Sleep disturbances in geriatric patients are a common symptom and are the result of decreased ability to maintain it. The reason is multi factorial like medical and psychiatric illness, medication, aging and sleep disorders. Among the most important risk factors identified are, cognitive impairment, environmental changes and treatment adjustments (Ancoli, 2006). Almost up to 90% of patients with moderate to severe dementia will present nocturnal agitation or hyperactivity sometime during their evolution (Ballard, 2001). The presence of these symptoms is related to longer hospitalizations. In the case of patients with severe dementia (Mini Mental State Examination) MMSE < 10, the follow up of behavioral problems is obligatory, on one hand to better follow up the efficacy of medical interventions. The use of antipsychotics for the treatment of BPSD is widespread. Between 23-40% in long stay units (Snowdown,2005). Taking into account that an important percentage occur during the night when less staff is available. This is a main cause for antipsychotics prescription, therefore trying to quantify nocturnal activity can be useful in order to adjust treatment and follow up sleep disorders and acute confusional states. The aim of this study was to evaluate a simple semi quantitative scale, designed by our team to be used by the night staff and compare it to a validated system of activity using Passive Infra Red Sensors (PIRS) called GARDIEN®.

## **6.2 Subjects and methods**

We used two patient bedrooms in our geriatric unit equipped with eight PIRS in different strategic locations to monitor elderly patients' activity. The network of sensors are connected to a computer, which uses an algorithm to calculate the duration of total activity, including bed, toilet and room activity, done exclusively by the patient. GARDIEN® has been validated by our team and is a good tool to quantify movement by actigraphy (Banerjee, 2004). We analyse the nocturnal activity from midnight until 6 o'clock in the morning in order to minimize interference due to the presence of other people in the room. We recruited inpatients that were hospitalized for at least 7 days and either the patient or their legal person in case of advance cognitive impairment, signed an informed consent. We chose patients with moderate to severe dementia MMSE (10-23) with known nocturnal activity and other subjects without dementia.

We proposed our assessment scale to the night staff, which was formed by a nurse and a nurse assistant. This scale was built with data obtained during an observational study of 1637 possible sequences of movements gathered in 147 nights<sup>5</sup>. The scale had 4 levels:

Score 0 = no observation of any mobility like getting up from the bed (peaceful night)

Score 1 = getting up from the bed once or two times (normal night)

Score 2 = getting up from the bed (more than > 2 times and less than 5) (mediocre night)

Score 3 = getting up from the bed (more than 5) (agitated or hyperactive night)

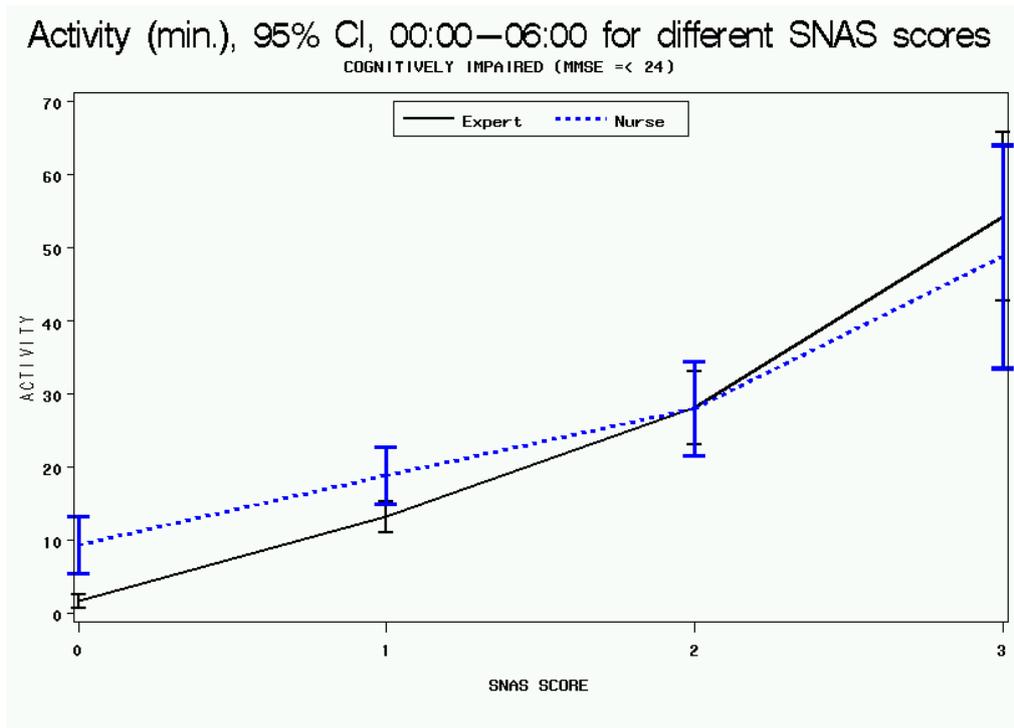
The night staff had to mark a score at the end of every night according to the observed patient's activity, installed in the two experimental bedrooms and they were blind to the actimetric data. Activity records were done during their regular hospital rounds from midnight until 6 o'clock (00:00, 03:00 and 06:00). The quality of the night is based on measurements including mobility out of the bed, mobility in the room or while going to the toilet. These definitions are standardized and

validated with GARDIEN®. We measured the cumulative nocturnal activity during the specified period (352 nights of observation) with GARDIEN ® and then compared it with the scale used by the night staff. In addition, the comparison was done between the observation made by the night staff and the evaluation made by three independent experts who were blind to the data. The experts used the GARDIEN ® results (actigraphic histograms and the automatic report) to fulfill our score. As a gold standard we chose the median score of the three experts. In the same way as we did for the night staff, we correlated this median score by experts with the cumulative nocturnal activity measured during the same specified period by the system.

### **6.3 Results**

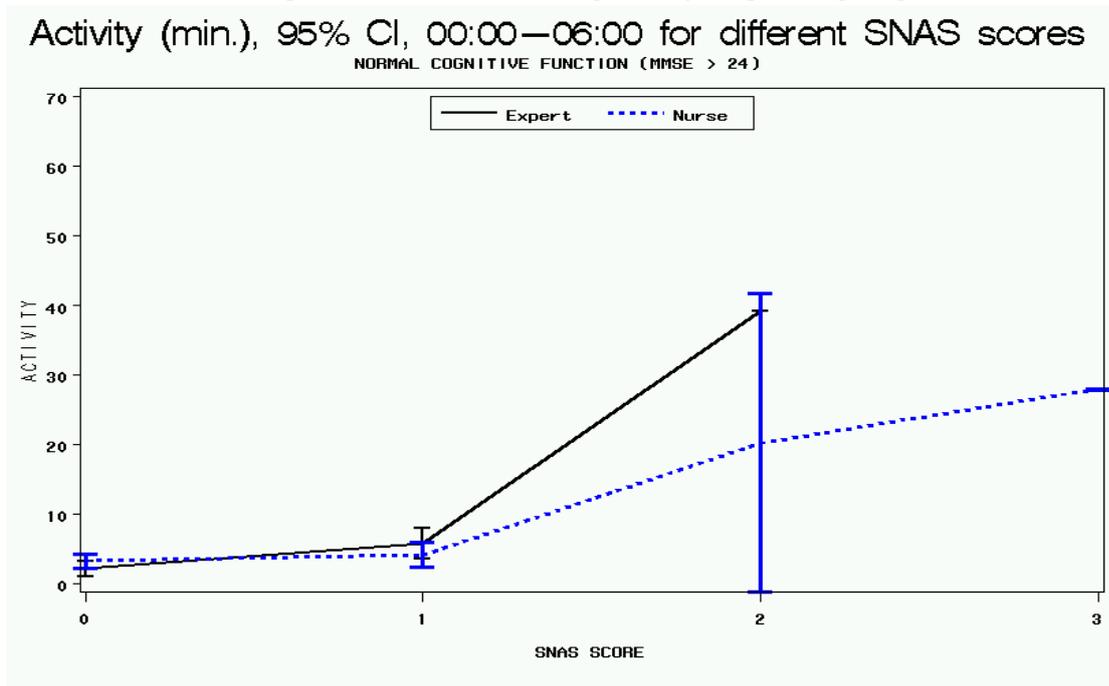
We registered a total of 352 nights gathered from 27 patients, 11men and 16women. Mean age was 82 years. All patients were hospitalized for medical reasons; including 19 with dementia of different types. The mean MMSE for these patients was 13/30.

In fig 6.1 we show the mean cumulative nocturnal activity with 95% confidence intervals for each score noted by the night staff and experts for the group with cognitive impairment. Scores showed a moderate agreement between staff and experts. And in figure 6.2 the same parameters but for the group without cognitive impairment. The weighted Cohen's kappa for the group with dementia was 0.45 and for the group without cognitive impairment 0.27. Overall agreement (weighted kappa) was 0.47 (95% CI, 0.40-0.53), for a total of 352 nights. We found that the mean nocturnal activity corresponds to a difference of approximately 10 minutes for the scores 0, 1 and 2, and score 3 is higher by approximately 20 minutes than that from the score 2 in the case of evaluation by night staff. (Data not shown). We presented the corresponding nocturnal activity levels for night staff and experts as a comparison between evaluation by two different and independent methods. The difference observed for the score 0 and 1 is related to the difficulties to appreciate a low level of movement or a simple getting up which cannot be easily identify during discontinuous clinical observation by night staff.



Weighted Cohen's kappa, = 0.45 (95% CI, 0.38-0.52). moderate agreement

**Fig.6.1. Mean total nocturnal (00:00-06:00) 'activity' ± 95% CI (min.) according to the SNAS score by expert and nurse in the 'cognitively' impaired group; N = 21**



Weighted Cohen's kappa, = 0.27 (95% CI, 0.08-0.46) *i.e.*, fair agreement (No. of nights = 57)

**Fig.6.2 Nocturnal activity measured from midnight to 6 am for the normal cognitive function group**

## **6.4 Discussion**

We find this evaluation scale a simple method to assess the quantity of nocturnal activity instead of long subjective reports usually done by night staff or it can be added to them.

The validity of the scale is higher in the group of cognitively impaired, so better suited for this population. The difference between the group of experts and staff is related to the difficulties to appreciate a low level of movement or a simple getting up by the staff group, probably due to a discontinuous observation during the night. According to this, the scale seems to be less efficient in normal patients with a normal low basal activity.

This scale gives a more objective overview of the patient's nocturnal activity than common records. Mainly because it is confronted to actimetric data that are cumulative and take into account all the movements during the night; this was considered as a gold standard. If low activity seems to be difficult to appreciate with this scale, high activity is easily evaluated. Evaluating agitation is one of the major goals in this type of patients. For instance a score 3 would indicate a possibility of nocturnal hyperactivity or agitation that distinguishes it from the other scores and alerts about the possibility of an acute confusional state due to a medical problems.

The results from our system depend on its own calibration, therefore activity measured by other systems such as actimetric bracelets can differ from those measured by our system. With wrist actigraphy four different categories in circadian activity have been shown in institutionalized elderly with dementia, proving the interest of measuring activity, especially during the night.

We have been using this system in the geriatric clinical practice and the night staff was felt comfortable and easily able to integrate this grading scale to their routinely patient's evaluation. This simple scale could help doctors to assess the level of patient's nocturnal activity in geriatrics, psychiatry and neurology wards, where nocturnal behavioral problems are common.

## **6.5 Conclusion**

Environmental actigraphy through PIRS can be used as a gold standard for the validation of a semiquantitative scale that estimates the level of nocturnal activity by personal staff. The scale has an acceptable kappa level that makes it a possible tool to increase performance in clinical records through more objective evaluations.

*Acknowledgements: The authors would like to acknowledge the patients, families, experts, and nurses, who participated in this research. The project was funded by France Alzheimer Association , Agrica and GRECO foundation.*

*See publication: Banerjee, 2009*

## **RESUME DU CHAPITRE 7**

Ce chapitre rassemble les points importants des études commentées et donne une vision sur les possibles utilisations des technologies innovatrices au bénéfice des personnes âgées. En gériatrie il y a un besoin de trouver des stratégies de prévention primaire, et précisément l'usage de certaines technologies permettra de le faire par la surveillance de l'état d'autonomie et ainsi de mieux reconnaître la fragilité. Dans le cas du patient en hospitalisation l'actimétrie par capteurs infra rouges, s'avère une méthode fiable et non invasive qui peut avoir plusieurs applications comme nous l'avons démontré. En ce qui concerne les contraintes éthiques pour tout ce qui concerne la gérontechnologie, le débat est ouvert, mais il n'existe pas encore de réglementations précises. Certaines technologies pourraient être intrusives mais sans doute moins que la plus part des gestes médicaux.

## CHAPTER 7 GENERAL DISCUSSION AND CONCLUSION

This chapter tries to summarize the main points, discussion and conclusion commented in previous chapters and gives a possible utilization of the exposed technologies to better help elderly keep integrated within the society. Solutions should be suitable to the two countries where this information should be tested in further studies.

Research on primary prevention strategies for most geriatric issues are urgently needed, given the high incidence and prevalence of problems like all the ones explained previously in this manuscript.

Therefore all the different type of interventions commented are justified and some of them show their potential to become new tools for the diagnosis and follow up of main issues like: autonomy, dependence, dementia and behavioral problems.

Differentiating between frail elderly or persons with some special needs or requirements for help in some tasks or ADLs is essential to develop public policy that legitimizes them. This will help to target interventions appropriately.

Otherwise we can risk of denying expensive and maybe high technological interventions, medical or not to some patients, while providing less expensive but inappropriate routine care to others.

Illness, autonomy, behavior in frail elderly should be compared to that of well elderly this is part of the principle of equity. We did show that environmental sensors can be a solution to this. An environment that can give reliable information on different type of data concerning health as well as other aspects of the individual like his daily performance is very important. It was mentioned that the risk of being too intrusive will always be there, but case by case it should be argued if the risk/benefice ratio justifies the intervention. This means that using technology at home is like using technology in the hospital when we mean performance. However the fact that technology is installed in the patient's home makes technology intrusive and special rules should apply, being the most important one the "informed consent".

Do we ask us each time while measuring the body temperature or the blood pressure if we are invading the subject's integrity, because we will use these data to decide or not an intervention? For sure not, since physicians do all kinds of invasive procedures in a highly technology environment call hospital that enables them to do so. Guidelines exist for most procedures and when it is a matter of

high risk, a signed informed consent is the rule. The right to be informed about the risks and benefits is imperative before any action is taken to avoid conflict from both sides.

Following this principle we could argue that we can also measure the level of activity of a person to know if he or she is at risk of becoming: dependent, frail or ill.

Since this type of studies require from a big technological intervention and human resources to install the infrastructure, this has not been cost effective, this would be the initial limitation of the system.

The main idea is that while technology advances and some technical problems can be resolved or simplified, end users will participate through this process so that realistic and cost effective outcomes can be reached. This is an important issue that was highlighted in chapter 2., the need to involve end users in the development process of innovative technologies.

For example in the MAPA study the persons involved, complain mainly about the installation of the system and the test re test period and third on the number of cables in their house, they felt rather uncomfortable at the beginning, but they got used to that. The phenomenon of "getting used" is human nature and technology is not an exception.

Now the problem has been resolved using a cable less devices and the users will not feel bother by cables all around their homes.

Another point is that we could evidence what was already known that one technology is not enough but the interaction of several types. The laboratory got involved in the MIDAS (Multimodal Interfaces for a Disabled and Ageing Society) project which like other big European projects uses several technologies that interact to offer a safer and adapted service to different types of users. We believe that the multi modality and interaction of different technologies is the solution for the future, because as human being technologies need from each other to improve their efficiency.

But respecting what concerns the exploitation of data by medical staff in hospital or other environment. Once again it can be argued in favor that medical staff is always "invading" people's privacy and that sometimes bothering by routinely procedures and losing time for a more human contact. Using technology could save time to health professionals while providing them useful information and in a more reliable way. For example the case commented in chapter 3. A person living alone at home with some moderate dementia who was being followed up by her physician on

regular basis. When she was asked if everything was ok at home she did answer YES. For sure she was feeling ok, but data recovered from the MAPA system showed that she started skipping meals and that her circadian rhythm was altered, then she was more and more active at night, or wandering around the house. Finally this patient loss weight and two weeks after her last medical visit she had an accident and broke her hip. Probably if we had analyze this data at the right moment and advice her physician, he would have act before and prevent this event. This was a first pilot study and therefore using data was out of the scope, but now we know the potential benefits of the access and use of these sensitive data. Therefore a new protocol is being prepared to go further and verify the real utility of such a system.

Research on the interaction among possible sensitive data about the person's health and autonomy is important in designing secondary and tertiary prevention programs. We need new working definitions on the outcomes we are finding with innovative technologies, especially if we are planning to integrate them to the routine evaluation in geriatrics.

The case of actigraphy has been widely exposed, it is not new and therefore guidelines exist. But for environmental actigraphy this is not the case, there are some publications on their usability and accuracy (Ancoli, 1995 ).

Since this type of studies require from a big technological intervention and human resources to install the infrastructure, this has not been cost effective, this would be the initial limitation of the system. But we are convinced that at least for hospital or institutional use it is a cost effective investment to install environmental sensors.

Along this manuscript we exposed three examples of the use of PIRS in a hospital room. First of all we did show that for instance using the GARDIEN system it was possible to find some difference in patterns about the nocturnal activity of patients with and without cognitive problems; how these differences were also related to the severity of their dementia. An important finding was to evidence the effect of the presence of depressive symptoms in this population, which will need further studies to be more precise about the possible interactions and causes. This result also should encourage geriatricians to be more sensitive to what happens during the night period, because important information about the evolution of the disease can be related to it. In general most physicians are aware of the existence of the nocturnal behavioral problems, but they are not really involved. As it was exemplify with the case in chapter 5, it is common that night staff is just reporting agitation during the night and then the physician reacts with a generous dose of psychotropic medications. Environmental actigraphy again here has shown its importance to easily and better observe nocturnal behavior without adding fastidious work to staff, on the contrary, we prove that in a not

negligible percentage of nights the staff did not report anything on the medical records and the system registered a high even abnormal high activity for that patient.

And even the system did function to validate a semi-qualitative scale, so that for those patients that cannot be in an equipped room with environmental sensors, then the SNAS scale can be an option. The scale is easy to use and has as main goal to better standardize nurses reports. As most scales it was designed to facilitate the evaluation and to have a standard score that enables a quick and more objective overview of what is happening during the night.

All the presented studies were done under an ethical framework, as it was explained in chapter 2, nowadays research even using technologies that apparently do not harm, are obligated to follow some guidelines. The regulation of this process needs to be highlighted and we hope that new dialogues will be open regarding this issues not still regulated. In the near future probably strict legislations will appear concerning the use and commercialization of innovative technologies like is the case for drugs, in order to avoid misuse and abuse.

## **7.2 Conclusion**

New technology for older persons with all its different applications, is a precious tool that can have a variety of applications everywhere, this means that its flexibility enables technology to be adapted to different societal models; for example the Mexican and the French one. Technology can be unlimited and intrusive if not regulated; therefore an ethical code and new legislations adapted to seniors are needed. The use of new technologies in the geriatric field is growing due to the acceptance of technology by this population and by the imminent need to better evaluate and survey elderly persons at home and in institutions. Technology has always been in touch with medical practice and it should be used to help ameliorate the quality of life of older persons. Environmental actigraphy can be an example of a new tool to evaluate autonomy at distance for persons living alone at home, it can help detect the risk frailty but its real impact needs to be shown in further studies. In the hospital environmental actigraphy by infrared sensors can have multiple uses and is a cost effective investment for a geriatric ward with patients with behavioral problems. Then it can add some objectiveness to clinical assessments and also discharge some work for the health personnel. As society evolves and ages at a fast speed technology has to be part of it, always following the right profile, then technology can age faster than a person and be obsolete in short time or it cannot be adapted to the needs of this population. The results shown in this work are a good example of the new applications of innovative technologies and their success relies on the multidisciplinary participation of technicians, researches, health professionals and the older person.

## CONCLUSION

Les nouvelles technologies au service des personnes âgées ont diverses applications. Elles peuvent s'adapter aux différents profils des usagers et contexte culturel. Les solutions technologiques apparaissent illimitées et peuvent devenir intrusive si leur utilisation n'est pas réglementée, raison pour laquelle des dispositions éthiques et une législation précise sont nécessaires. Il est important d'inclure les usagers lors du développement de ces nouvelles technologies, car leur opinion est primordiale pour que le résultat soit réaliste et adapté à leurs besoins physiques, psychiques et environnementaux. La technologie a toujours été présente dans le milieu médical et peut être utilisée pour l'évaluation clinique, l'amélioration de la qualité des soins, et de la qualité de vie des personnes âgées. Elle peut également être utilisée pour aider les professionnels dans l'évaluation et la prise en charge des patients. Ainsi nous avons montré que l'actimétrie de l'environnement par capteurs infra rouges permet une meilleure compréhension du comportement chez les patients déments avec troubles du comportement. Elle peut être utile pour le suivi des interventions médicamenteuses et nous a permis de valider une échelle d'évaluation du comportement nocturne en milieu hospitalier. A domicile les applications de l'actimétrie par d'autres type des capteurs apparaît faisable notamment pour apprécier le niveau d'autonomie dans les activités de la vie courante, une variable capitale de l'évaluation gériatrique standardisée. L'actimétrie d'environnement s'avère ainsi très utile pour l'évaluation du sujet âgé fragile à domicile ou à l'hôpital et constitue à moyen terme une aide précieuse pour le clinicien et l'entourage familial ou professionnel.

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# LIST OF SCIENTIFIC MEETINGS WHERE PARTS OF THIS WORK WERE PRESENTED

## Posters

### **1. Silver Congress of the International Psychogeriatric Association**

14-18 October 2007, Osaka, Japan

#### Publication 1:

Couturier P; **Corte G**, Gallay F; Berenguer M; Mourrain C. A new Approach of home surveillance for autonomous in home patients with mild dementia. International Psychogeriatrics 2007; Vol 19;19: 280-281.

### **2. Journées de la Recherche médicale 2008**

Faculté de Médecine de la Université Joseph Fourier- CHU Grenoble  
23 -25 Mai 2008

### **3. 28èmes Journées Annuelles de la Société Française de Gériatrie et Gériatologie**

23-25 October, 2007, Paris France

#### Publication 2

**G Corte**, F Gallay, M Berenguer, C Mourrain, P Couturier. Evaluation d'un nouveau système de télémonitoring des activités de la vie quotidienne à domicile pour le dépistage de la perte d'autonomie des personnes âgées fragiles. L'Année Gériatologique, Vol 21,T 2:82-83

### **4. 9ème Réunion Francophone sur la Maladie d' Alzheimer et les syndromes apparentés**

20-22 November, Nice, France, 2007

#### Publication 3:

**G Corte**, F Gallay, M Berenguer, C Mourrain et P Couturier Nouvelle technique de Télévigilance pour la supervision des patients déments à domicile résultats préliminaires. Rev Neurol. 2007;11pt 2, 4S130-4S131.

## **5. 19th world Congress of the International Society of Gerontology,**

July 5-9, Paris, France, 2009

### Publication 4

**G. Corte-Franco** MD, MMSc, S. Banerjee MD, PhD F. Steenkeste , P. Moulin, P. Couturier MD, PhD  
Evaluating Nocturnal Motor activity of demented inpatients by a short semi quantitative scale. JNHA,  
2009, Vol13, Suppl 1: S448

### Publication 5

Soutrik BANERJEE, MD PhD, **Georgina CORTE FRANCO**, MD, François STEENKESTE, Pascal  
COUTURIER, MD PhD. Nocturnal wandering and cognitive function: cross-sectional and longitudinal  
study of elderly inpatients in France. JNHA 2009, Vol13, Suppl 1: S275.

## **6. 14th International Congress of the International Psychogeriatric Association**

1-5 September, 2009, Montréal, Canada

### Publication 6:

S Banerjee, **G Franco**, P Moulin, F Steenkeste, P Couturier. Evaluating nocturnal activity in demented  
inpatients by a short semi-qualitative scale. International Psychogeriatrics 2009, Vol 21 Suppl 2: S  
168

## **7. 10è Réunion Francophone sur la Maladie d'Alzheimer et les syndromes apparentés**

20-22 OCTOBER 2009, Nantes, France

### Publication 7:

**Corte-Franco G**, Banerjee S, Millet C, Ouzaid K, Couturier P. Analyse de l'activité motrice nocturne  
chez les patients avec troubles psycho-comportementaux par chambre actimétrique : A propos d'un  
cas. Revue Neurologique, 2009. Vol 165, Issue 10, Suppl 1: 83-84.

## **8. Congress from the International Association of Sleep Research in Gerontology**

Aging and Sleep, 2010, 25 -26 June, Lyon, France

**Poster n: 30F**

# LIST OF ANNEXES

## ANNEXE 1

### FORMULAIRE D'INFORMATION ET DE CONSENTEMENT POUR UNE PERSONNE PARTICIPANT A UNE RECHERCHE BIOMEDICALE

Le Docteur \_\_\_\_\_ m'a proposé de participer à la recherche intitulée « Evaluation du Comportement moteur nocturne dans la démence sévère par chambre actimétrique et détection des errances nocturnes. Le médecin m'a précisé que j'étais libre d'accepter ou de refuser de participer à cette recherche. Afin d'éclairer ma décision, j'ai reçu et bien compris les informations suivantes :

Il s'agit de participer à une étude au Centre Hospitalier de Grenoble visant à mieux comprendre les difficultés de la prise en charge des troubles du comportement nocturnes chez des patients ayant des troubles cognitifs évolués.

Cette étude inclut 30 patients hospitalisées dans le Pavillon E. Chatin en SSR au deuxième étage dans le CHU de Grenoble.

La participation à cette recherche comprend:

- un entretien et le recueil d'informations à travers le remplissage de différents questionnaires d'évaluations qui seront effectués par le docteur Georgina CORTE, médecin gériatre et thésard en sciences médicales. La durée de l'entretien est d'environ  $\frac{3}{4}$  d'heure. Les thèmes abordés concerneront mon vécu de la prise en charge au quotidien et son retentissement sur ma qualité de vie.
- Et l'enregistrement de l'activité physique, fait par des capteurs du mouvement qui sont placés dans la chambre du patient et que ne interfèrent pas avec ses activités de soins ou de la vie quotidienne.

J'accepte que les données médicales me concernant ainsi que celles relatives à mes habitudes de vie recueillies à l'occasion de cette recherche puisse faire l'objet d'un traitement informatisé par les organisateurs de la recherche.

Les données recueillies resteront strictement confidentielles. Elles ne pourront être consultées que par l'équipe médicale, les personnes dûment mandatées par le promoteur de la recherche et éventuellement par des représentants des autorités sanitaires et judiciaires habilitées.

Après en avoir discuté et avoir obtenu réponse à toutes mes questions, j'accepte librement et volontairement de participer à la recherche décrite ci-dessus. Je suis parfaitement conscient(e) que je peux retirer à tout moment mon consentement à ma participation à cette recherche et cela quelles que soient les raisons et sans supporter aucune responsabilité. Le fait de ne plus participer à cette recherche ne portera pas atteinte à mes relations avec le médecin investigateur.

Si je le souhaite, à son terme, je serai informé(e) par l'investigateur qui recueille mon consentement des résultats globaux de cette recherche.

L'investigateur :

Personne donnant le consentement :

Fait à ....., le.....

Fait à ....., le.....

Nom, prénom : .....

Nom, prénom : .....

Signature

Signature

## ANNEXE 2

### KATZ INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

<b>Activities</b>	<b>Independence</b>	<b>Dependence</b>
Points (1 or 0)	(1 Point)	(0 Points)
BATHING Points: _____	NO supervision, direction or personal assistance  (1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity	WITH supervision, direction, personal assistance or total care  (0 POINTS) Need help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing
DRESSING Points: _____	(1 POINT) Get clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TOILETING Points: _____	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING Points: _____	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transfer aids are acceptable	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE Points: _____	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder
FEEDING Points: _____	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.
Total Points: _____		

Score of 0 = Low, patient is very dependent.

\*\*Slightly adapted. Katz S., Down, TD, Cash, HR, et al. (1970) progress in the development of the index of ADL. Gerontologist 10:20-30. Copyright The Gerontological Society of America. Reproduced by permission of the publisher.

## **ANNEXE 3**

### **INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADL)**

#### **A. Ability to use telephone**

1. Operates telephone on own initiative; looks up and dials numbers, etc.
2. Dials a few well-known numbers
3. Answers telephone but does not dial
4. Does not use telephone at all.

#### **B. Shopping**

1. Takes care of all shopping needs independently
2. Shops independently for small purchases
3. Needs to be accompanied on any shopping trip.
4. Completely unable to shop.
5. medication.

#### **C. Food Preparation**

1. Plans, prepares and serves adequate meals Independently.
2. Prepares adequate meals if supplied with Ingredients
3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet.
4. Needs to have meals prepared and served.

#### **D. Housekeeping**

1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help")
2. Performs light daily tasks such as dishwashing, bed making
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.
4. Needs help with all home maintenance tasks.
5. Does not participate in any housekeeping tasks.

#### **1 E. Laundry**

1. Does personal laundry completely
2. Launders small items; rinses stockings, etc.
3. All laundry must be done by others.

#### **F. Mode of Transportation**

1. Travels independently on public transportation or drives own car.
2. Arranges own travel via taxi, but does not otherwise use public transportation.
3. Travels on public transportation when accompanied by another.
4. Travel limited to taxi or automobile with assistance of another.
5. Does not travel at all.

#### **G. Responsibility for own medications**

1. Is responsible for taking medication in correct dosages at correct time.
2. Takes responsibility if medication is prepared in advance in separate dosage.
3. Is not capable of dispensing own

#### **H. Ability to Handle Finances**

1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income.
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.
3. Incapable if handling money.

**Source:** Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." *Gerontologist* 9:179-186, (1969).

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## ANNEXE 4

### MINI MENTAL STATE EXAMINATION (MMSE) (VERSION CONSENSUELLE DU GRECO)

Orientation / 10

<b>Je vais vous poser quelques questions pour apprécier comment fonctionne votre mémoire.</b>	Les unes sont très simples, les autres un peu moins. Vous devez répondre du mieux que vous pouvez.
<b>Quelle est la date complète d'aujourd'hui ?</b>	Si la réponse est incorrecte ou incomplète, posez les questions restées sans réponse, dans l'ordre suivant :
<b>1. En quelle année sommes-nous ?</b>	<b>2. En quelle saison ?</b>
<b>3. En quel mois ?</b>	<b>4. Quel jour du mois ?</b>
<b>5. Quel jour de la semaine ?</b>	Je vais vous poser maintenant quelques questions sur l'endroit où nous trouvons.
<b>6. Quel est le nom de l'hôpital où nous sommes ?*</b>	<b>7. Dans quelle ville se trouve-t-il ?</b>
<b>8. Quel est le nom du département dans lequel est située cette ville ?**</b>	<b>9. Dans quelle province ou région est située ce département ?</b>
<b>10. A quel étage sommes-nous ?</b>	<b>Apprentissage / 3</b>
<b>Je vais vous dire trois mots ; je vous voudrais que vous me les répétiez et que vous essayiez de les retenir</b>	car je vous les redemanderai tout à l'heure.
<b>11. Cigare Citron Fauteuil</b>	<b>12. Fleur ou Clé ou Tulipe</b>
<b>13. Porte Ballon Canard</b>	Répéter les 3 mots.
Attention et calcul / 5	Voulez-vous compter à partir de 100 en retirant 7 à chaque fois ?*
<b>14. 93</b>	<b>15. 86</b>
<b>16. 79</b>	<b>17. 72</b>
<b>18. 65</b>	Pour tous les sujets, même pour ceux qui ont obtenu le maximum de points, demander :
<b>Voulez-vous épeler le mot MONDE à l'envers ?**</b>	<b>Rappel / 3</b>
<b>Pouvez-vous me dire quels étaient les 3 mots que je vous ai demandés de répéter et de retenir tout à l'heure ?</b>	<b>11. Cigare Citron Fauteuil</b>
<b>12. Fleur ou Clé ou Tulipe</b>	<b>13. Porte Ballon Canard</b>
Langage / 8	Montrer un crayon. <b>22. Quel est le nom de cet objet ?*</b>
<b>Montrer votre montre. 23. Quel est le nom de cet objet ?**</b>	<b>24. Ecoutez bien et répétez après moi : « PAS DE MAIS, DE SI, NI DE ET »***</b>

## ANNEXE 5

### GERIATRIC DEPRESSION SCALE (GDS)

1. Are you basically satisfied with your life ?	15 Do you think it is wonderful to be alive now ?
2. Have you dropped many of your activities and interests ?	16 Do you often feel downhearted and blue ?
3. Do you feel that your life is empty ?	17 Do you feel pretty worthless the way you are now
4. Do you often get bored ?	18 Do you worry a lot about the past ?
5. Are you hopeful about the future ?	19 Do you find life very exciting ?
6. Are you bothered by thoughts you can't get out of your head ?	20 Is it hard for you to get started on new projects ?
7. Are you in good spirits most of the time ?	21 Do you feel full of energy ?
8. Are you afraid that something bad is going to happen to you ?	22 Do you feel that your situation is hopeless ?
9. Do you feel happy most of the time ?	23 Do you think that most people are better off than you are ?
10. Do you often feel helpless ?	24 Do you frequently get upset over little things ?
11. Do you often get restless and fidgety ?	25 Do you frequently feel like crying ?
12. Do you prefer to stay at home, rather than going out and doing new things ?	26 Do you have trouble concentrating ?
13. Do you frequently worry about the future ?	27 Do you enjoy getting up in the morning ?
14. Do you feel you have more problems with memory than most ?	28 Do you prefer to avoid social gatherings ?
	29 Is it easy for you to make decisions ?
	30 Is your mind as clear as it used to be ?

This is the original scoring for the scale: One point for each of these answers. Cutoff: normal-0-9; mild depressives-10-19; severe depressives-20-30

*Source. Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey MB, Leirer VO: Development and validation of a geriatric depression screening scale: A preliminary report. Journal of Psychiatric Research 17: 37-49, 1983*

**ANNEXE 6**  
**PUBLICATION ABOUT CHAPTER 3**

JTT-07-12-007

RESEARCH

Original article

► **Non-invasive monitoring of the activities of daily living of elderly people at home – a pilot study of the usage of domestic appliances**

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**Summary**

We conducted a feasibility study of a system for non-invasive monitoring of subjects at home. Electrical activity was recorded from room lights and from electrical domestic appliances; this was translated into the probability of physical activity or a particular Activity of Daily Living (ADL). Thirteen volunteer subjects were monitored for a period of 6.4 months (range 3–8). The mean age of the subjects was 80 years and they all lived alone at home; one had moderate Alzheimer's disease. A one-week validation was carried out to ascertain whether the recorded activity actually occurred. The results showed that daily and nocturnal activity could be well differentiated. The probability of having eaten, taken a bath and going to the toilet could be calculated each day. Eating was the most accurately measured ADL; toileting and bathing results were less accurate. The system appears to be a promising component of home telecare.

**Introduction**

The importance of daily health monitoring at home in order to evaluate health status and quality of life has been proposed by Dittmar *et al.*<sup>1</sup> Some authors have developed the concept of continuous monitoring using different sensors in order to model human activity in their home.<sup>2</sup> A few clinical applications have been proposed in the field of home surveillance, mostly based on an identifiable routine of activity. Some publications have described the use of different types of sensors for recording movement or temperature or activity. Le Bellego *et al.* used a hospital suite simulating a person's home, equipped with a network of passive infra red (PIR) sensors in order to study activity, mobility, occupation and agitation.<sup>3</sup> The use of infrared sensors to detect an occupancy pattern in an experimental room has also been studied by other groups, but accuracy remains to be proved in different types of rooms, since the detector output depends on the velocity of movement and the distance.<sup>4</sup>

Calculating energy expenditure for elderly people at home using these types of sensors has also been proposed by Kaushil and Celler.<sup>5</sup> This has been tested in an experimental set-up. Although the results were promising,

the principal problem was that sensors could not differentiate the test subject when more than one person was present in the space being monitored.

Recognition of posture using a 3-D camera has also been tested, but the system was tested with a younger person. The results were promising: the system was capable of classifying position as standing, sitting or lying down.<sup>6</sup>

Bonhomme *et al.* proposed extending their system which was based on a presence sensor to the environment of the home, but keeping wearable sensors to enhance sensitivity; this would probably not be suitable for persons with cognitive problems.<sup>7</sup> Nowadays the goal is to monitor people at home in order to keep them safe and in good conditions. Suzuki *et al.*<sup>8</sup> used a combination of sensors to follow a person living independently alone at home. They were able to identify a pattern of daily activities that allowed monitoring and detection of possible anomalies.

We have conducted a pilot study of a new method of surveillance at home based on recording the electricity used by light fittings and common electrical domestic appliances (EDAs). The aim of the present study was to test the acceptability of this method of non-invasive monitoring.

**Methods**

Subjects from the Rhône-Alpes Region of France were selected between May and August 2005. They were recruited

Accepted 30 March 2008  
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## ANNEXE 7

### PUBLICATION ABOUT CHAPTER 3

#### **ALZHEIMER2007/134**

#### **Nouvelle technique de télévigilance pour la supervision des patients déments à domicile : résultats préliminaires**

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En France environ 90.3 % des patients déments vivent à domicile, avec des risques liés à la perte d'autonomie souvent insidieux, difficiles à évaluer et révélés souvent tardivement au stade des troubles psycho-comportementaux. Objectif : Evaluer l'efficacité d'un système de surveillance non embarqué qui permet de suivre les malades dans les différents actes de la vie quotidienne par l'enregistrement des signaux électriques du domicile : éclairage et appareils électroménagers et tester son efficacité dans un échantillon de patients âgés et chez un patient Alzheimer. Sujets: personnes autonomes à domicile vivant seules et sans troubles cognitifs sévères, ayant un médecin référent et capables de donner un consentement éclairé. Méthode : Installation du système à domicile en présence du sujet pour sélectionner les appareils électroménagers les plus utilisés. Vérification que l'activité enregistrée correspond bien aux AVQ sur une semaine Evaluation par téléphone réalisée par un gériatre pour mesurer l'état de santé et le niveau de fragilité. Résultat : 11 femmes et 2 hommes, d'âge moyen 80 ans (68-89) ont été suivis pour une période de 6.4 mois (3-8.). Le nombre d'appareils enregistrés par foyer était de 20 (11-28). Concernant l'acceptabilité du système, 12 personnes se sont senties en sécurité et non surveillées (10 ont oublié l'existence du système). Tous voudraient avoir un retour d'information et pensent que c'est leur médecin traitant la personne la plus indiquée pour suivre les données Le système permet d'établir des histogrammes donnant la probabilité (en %) d'avoir effectué des activités diurnes ou nocturnes, utiliser les WC, réaliser les repas et effectuer sa toilette selon une analyse journalière, hebdomadaire ou sur toute la période d'étude. Pour chaque individu une activité "normative " peut être établie ce qui permet d'identifier les variations d'activité. Le patient Alzheimer montrait un histogramme avec une activité nocturne régulièrement élevée (déambulation), une activité diurne irrégulière avec un impact sur la nutrition. Le suivi médical a montré une perte de poids, une perception de fatigue non expliquée et quelques mois après l'étude elle a présenté une chute avec complications Conclusion: ce système est capable d'identifier les sujets à risque de troubles psycho comportementaux, notamment nocturne et peut s'avérer utile dans l'aide à la vigilance des aidants.

Nombre de mots du résumé: 352

Mots-clé: télévigilance - à domicile - nouvelle technique

Thème: Prise en charge globale, Gériatrie

Session spéciale: Non spécifié(e)

Présentation: Présentation poster de préférence

Equipement particulier: Pas d'équipement particulier

Inscription: - -

## ANNEXE 8

### PUBLICATION ABOUT CHAPTER 5

#### **ALZHEIMER2009/131**

#### **Analyse de l'Activité Motrice Nocturne chez les Patients avec Troubles Psycho-comportementaux par Chambre Actimétrique : A propos d'un Cas**

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**INTRODUCTION** Les troubles du comportement chez les déments sont fréquents. L'agitation, l'agressivité et la déambulation sont difficiles à gérer et source de stress pour l'équipe soignante et l'entourage. Ces complications sont plus fréquentes le soir avec le " sundowning " et la nuit avec l'inversion du cycle veille sommeil. L'apparition d'un état confusionnel aigu sur un syndrome démentiel peut révéler la présence d'une pathologie sous-jacente ou bien un trouble métabolique. Le repérage de ces troubles par une meilleure connaissance de l'activité nocturne peut aider à gérer ces patients et éviter l'abus des neuroleptiques.

**MATERIEL/METHODE** Nous présentons le cas d'un homme de 79 ans suivi par actimétrie environnementale en utilisant le système GARDIEN® qui comporte 8 capteurs infra rouges dans une chambre d'hospitalisation. Le système reconnaît la présence du personnel dans la chambre et cette activité n'est pas prise en compte. M.B qui était connu pour une démence mixte et un diabète insulino requérant est arrivé confus et agressif aux urgences avant d'être hospitalisé en gériatrie. Les données des transmissions infirmières ont été comparées avec celles obtenus par le système GARDIEN® par un expert indépendant.

**RESULTAT** Nous avons enregistré 75 nuits sur une période de 4 mois. La moyenne d'activité entre minuit et 6 h était de 17.9 minutes et entre 21 et 6h de 35 minutes ce qui est élevé en comparaison aux groupe de référence. Le patient a présenté des pics d'hyperactivité nocturne a plusieurs reprise qui ne correspondent pas toujours aux rapports des soignants. Le système apparait plus fiable pour identifier une hyperactivité en lien avec une altération métabolique (hyper ou hypoglycémie). L'actimétrie révèle cependant un pattern de stabilisation comportemental chez ce patient dément dont le MMSE au départ de 11/30 est passé à 21/30 après 23 jours suggérant le contrôle de l'état confusionnel.

**CONCLUSION** L'actimétrie peut être utile pour la surveillance des troubles du comportement surtout nocturne et révéler des pathologies intercurrentes chez le patient dément.

Nombre de mots du résumé: 315

Mots-clé: démence - troubles du comportement - actimétrie environnementale

Thème: Clinique - Neuropsychologie et comportement

Session spéciale: Non spécifié(e)

Présentation: Pas de préférence

Equipement particulier: Pas d'équipement particulier

Inscription: - -

## ANNEXE 9

### PUBLICATION ABOUT CHAPTER 6

graphy did not identify ischemia or infarction in the myocardial territories supplied by the LAD, but there was a false-positive result for the inferior segment. Differentiation of the LAD proper from a total occlusion with developed collateral circulation is crucial, especially in older individuals with cardiovascular risk factors, to avoid an unnecessary revascularization procedure. Mapping of the perfusion of all myocardial segments supplied by the arteries visualized may be vital to avoid incomplete or unnecessary revascularization procedures.

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#### ACKNOWLEDGMENTS

All authors are members of the Turkish Society of Cardiology.

**Conflict of Interest:** The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this letter.

**Author Contributions:** All the authors contributed to the composition of this letter.

**Sponsor's Role:** None.

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#### A SHORT NOCTURNAL ACTIVITY SCALE USED BY NURSES TO EVALUATE HOSPITALIZED PATIENTS WITH DEMENTIA

*To the Editor:* Sleep disturbances in geriatric patients are common. The important risk factors are cognitive impairment, environmental changes, and treatment modifications.<sup>1</sup> Behavioral problems such as agitation frequently occur at night, when physicians are not on their regular ward visits.<sup>2</sup> For this reason, quantitative assessment of nocturnal activity by nurses could be useful.

The objective of this study was to evaluate a categorical scale for assessing nocturnal activity in geriatric inpatients by nurses and compare it with experts' scores evaluated on a validated system of measuring inpatient activity using passive infra-red sensors (PIRSs).

#### METHODS

Two bedrooms were recruited within the geriatric department equipped with eight PIRSs. These were connected through cable network to a remote computer. This system, GARDIEN François Steenkeste, INSERM U.558, Toulouse, France, has been previously validated.<sup>3,4</sup> Patients, who had been hospitalized for at least 8 days, were selected. Patient activity was measured from midnight until 6:00 a.m. for at least 8 nights. The patient or legal guardian signed the informed consent. Twenty-one patients with mild-to-severe dementia (Mini-Mental State Examination (MMSE) scores 4-24 (the cognitively impaired group)) and six elderly patients without dementia (MMSE scores  $\geq 25$  (the normal cognitive function group)) participated in this study.

A short nocturnal activity scale (SNAS) for patient nocturnal activity assessment was proposed to the nurses with score definitions as follows

- 0 = no observed activity in toilet or room
- 1 = observed activity in toilet or room at one or two distinct times
- 2 = observed activity in toilet or room at three to five distinct times
- 3 = observed activity in toilet or room at six or more distinct times (hyperactive night)

The nurses noted a score at the end of a night's observation according to their overall impression of patient activity. Three experts were independently provided with automated daily reports by GARDIEN consisting of a histogram of patient activity according to PIRS every 15 minutes and a report with start and end times and a description of the movements interpreted by the system with a summary of the duration of bed, toilet, room, and total activities. They similarly noted a score on each night's activity. The median score of the three experts was chosen as a reference.

The interrater agreement between the two comparators (nurses and experts) was calculated using the weighted Cohen kappa statistic in both groups. All statistical calculations were performed using SAS version 9.1.3 (SAS Institute, Inc., Cary, NC).

Presented as a poster at the Nineteenth International Association of Gerontology Congress, Paris, July 5 to 9, 2009, and in the "Journées FMC de la Société Française de Gériatrie et Gérontologie," October 6, 2008; the abstract was published in French in *L'Année Gériatrique* 2008;22(suppl 2): 169-170, and in *JNHA* 2008;13(suppl 1):448.