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IAGG WORKSHOP

IDENTIFICATION OF THE MAIN DOMAINS FOR QUALITY OF CARE AND CLINICAL RESEARCH IN NURSING HOMES

Y. ROLLAND[1], J.-P. AQUINO[2], S. ANDRIEU[3], J. BEARD[4], A. BENETOS[5], G. BERRUT[6], L. COLL-PLANAS[7], J.-F. DARTIGUES[8], B.R. DONG[9], F. FORETTE[10], A. FRANCO[11], S. FRANZONI[12], T. HORNEZ[13], P. METAIS[14], G. RUAULT[15], E. STEPHAN[16], D. SWAGERTY[17], D. TOLSON[18], L. VOLICER[19], B. VELLAS[20], J. MORLEY[21]

1. Professor of Medicine at Toulouse University Hospital, France; 2. President of SFGG (Société Française de Gériatrie et de Gérontologie), France; 3. Professor of Public Health at the Toulouse University Hospital and is Head of the Aging and Alzheimer Disease research team (UMR1027 INSERM-Université Paul Sabatier), France; 4. WHO, Director of Department of Ageing and Life Course, Switzerland; 5. Professor of Internal Medicine and Geriatrics, Head of the Department of Geriatrics, Nancy University Hospital, France; 6. Vice-President of the SFGG (Société Française de Gériatrie et de Gérontologie), Professor of Medicine and Chief of Geriatric Medical Department at the Nantes University Hospital, France; 7. Medical doctor and researcher at the Institut de l'Envelliment of the Universitat Autonoma de Barcelona, Spain; 8. Neurologist and Professor of Public Health at the Bordeaux University Hospital, France; 9. Head of the Department of Geriatrics, West China Hospital of Sichuan University, China; 10. President of ILC-France (International Longevity Centre), Professor of internal medicine and geriatrics at University Paris V, Director of the FNG (Fondation Nationale de la Gériatrie), France; 11. Professor of Internal Medicine and Geriatric Medicine at the Nice University, Hospital and President the International Society for Gerontechnology, France; 12. Director Research Group on Geriatrics of the University of Rome, President of the Italian Psychogeriatric Association, Italy; 13. Director of the Recommendation Service of the ANESM (Agence Nationale de l'Evaluation et de la Qualité des Etablissements et Services Sociaux et Médico-Sociaux), France; 14. Medical Director of CLINEA, the clinical facilities of ORPEA Group, France; 15. SFGG General Representative, Coordinator of the MobiQual (Mobilisation pour l'amélioration de la Qualité des Soins) program, France; 16. Associate Professor in Clinical Medicine, Family Medicine and Geriatrics, Head Geriatric Acute Unit St George Hospital Beyrouth, Balamand University Lebanon; 17. Professor of Family Medicine and Internal Medicine, Director of Clinical Geriatrics and Palliative Care, Associate Director (Education) of the Landon Center on Aging, University of Kansas School of Medicine, USA; 18. Professor of Gerontological Nursing at Glasgow Caledonian University, Director of the Scottish Centre for Evidence Based Care of Older People, United Kingdom; 19. Professor at the School of Aging Studies, University of South Florida, Tampa, USA; 20. President of IAGG, Professor of Medicine, Chief Department of Internal Medicine and Geriatrics, Chief of Alzheimer's Disease Clinical Research Centre, Toulouse University Hospital, France; 21. Professor of Medicine at the Saint Louis University Medical Center, USA

ROADMAP FOR BETTER CARE IN NURSING HOMES

Y. ROLLAND[1], D. TOLSON[2], B. VELLAS[1], J.E. MORLEY[3]

1. Department of Geriatric Medicine, Toulouse University Hospital, INSERM 1027, Toulouse, France; 2. Glasgow Caledonian University, Glasgow, UK; 3. Division of Geriatric Medicine, Saint Louis University & GRECC VA Medical Center, St. Louis, MO, USA

Despite considerable differences between nursing homes around the world, there is a growing international awareness of the need to perform high quality care in nursing homes. Currently, between 4 to 10% of older people in the United States, United Kingdom or France live in nursing homes and a large majority of older people will be admitted to a nursing home and eventually die there. As developed countries face an aging population, the number of older people living in nursing homes will continue to increase.

Residents of nursing homes differ from other patients in many respects. Most older people living in the nursing home have lost independence to live in the community through illness, disability and frailty. In France, the mean age is about 84 years in the nursing home, 20% are bedridden, 36% are severely dependant, with a mean number of co-morbidity of eight (1). This population is exposed to complex clinical conditions, to high risk of iatrogenic events, functional decline, and death, and need an expert management (2). Evidence supports that clinical outcomes in the nursing home rely on geriatric approaches and leadership (3, 4).

The nursing home objectives are not just for meeting specific medical care needs but also to fulfill psychological and social needs and to improve quality of life through environment, meaningful activities and social contacts. To reach these different core tasks, skilled geriatric competences are required from the whole staff. This multidimensional approach is complex and defines the quality of care of a nursing home.

Unfortunately, the recognition of the unique skill of the nursing home staff is low. This results in a high rate of nurse and nursing assistant turnover and a high rate of vacancies that impact on the quality of care. This feeling of lack of recognition is reinforced by the general perception of lack of resources and frequent confrontation with vulnerable families under pressure from psychological and economic conditions. Nursing home admission is still often an expensive default choice for the patient and his relatives.

Academic support and input in nursing home care has been weak. Clinical research on nursing home residents are still scarce compared to research performed in community-dwelling elderly population. In 2011, we have to conclude that most clinical protocols applied to nursing home residents rely on very little scientific background. The least evidence is available for care of the group at greatest risk.

In this context, the International Association of Gerontology and Geriatrics (IAGG) and the World Health Organization (WHO) organized a task force focused on specific needs for nursing homes residents, priority actions and future researches for the purpose of enhancing care provided to older people

living in nursing homes (5).

The group proposed recommendations across four main core domains:

- the enhancement of reputation of nursing home practice and leadership,
- the clinical essentials and care quality indicators,
- practice education,
- research.

Among the 15 recommendations, the task force recognized that effective outcomes in the nursing home rely on the collaborative leadership between the nursing director, the medical expert in geriatrics and a skilled administrator. The group called for appropriate indicators of quality of care that correspond to the residents needs but also indicators which demonstrate dignified and respectful care.

'Meaningful activities' such as physical exercise or mind expanding games, respectful to elders' preferences and mindful to the resident cultural sensitivity should be developed. These non-pharmacological approaches can enhance both health and quality of life.

A lot of nursing homes continue to use physical and chemical restraints. This abusive form of maltreatment should be avoided as far as possible and be a quality nursing care indicator (2). The management of behavior disturbances in demented patients should rely first on an effective alternative to antipsychotics (6, 7).

The prevalence of pain and symptoms requiring palliative care is high in nursing homes. Quality improvement of end-of-life cares require continuous educational initiatives among medical and nursing staff for residents (8, 9). Pain management and organization of palliative care programs should be a priority of high quality nursing home cares.

Nursing home residents are a vulnerable population that has been usually excluded from research programs. Subject to the application of acceptable ethical approaches, nursing home research should be supported and nursing home residents should be included in drug trials before drug agencies approval. Research aims should be appropriate to specific priority of this population such as functional decline, cognitive decline, behavior disturbances or weight loss (10). This is a new area of investigation and a great opportunity for nurses to develop nursing research and make major contributions to enhance quality of care in the nursing home.

Improvement of quality of care supposes innovative educational programs for nursing homes staff including certified nurses' aides. Nurses' aides play a major role and should be involved in each effort. One of the challenges for the members of nursing staff is to work in his respective fields but with synergic action. These efforts have to be lead by collaborative effort of expert physicians and nurses and administrators together (11). The group also highlighted that a key factor in advancing high quality care is to enhance recognition of the nursing home staff to reduce health professional shortage and the high rate of turnover (12). Work with nursing home residents should be socially valued, supported by politicians for human and technical investment (13) and properly paid, in order to attract a highly qualified workforce.

We hope that these recommendations will be carried forward to enhanced quality of care in nursing home throughout the world.

FROM EPIDEMIOLOGICAL AND CLINICAL RESEARCH TO MODELS OF CARE,

L. Coll-Planas, A. Salvà (Spain)

In this paper, we focus on the situation of nursing homes within Long-Term Care in Catalonia, an autonomous community within Spain. We will approach the topic of research and quality of care in nursing homes in our country following the next areas: epidemiological and clinical research, research on the models of care and research on clinical management. Last, we will point out some limitations and possibilities of research in nursing homes.

Epidemiological studies and clinical research

On behalf of the Health Department of Catalonia, our Institute on Aging conducted in 2008 the first descriptive epidemiological study on the health status of people living in nursing homes. The study is called ESPI (1) (Estat de Salut de Persones Institucionalitzades) and is on process of being published. Until then, periodically conducted epidemiological studies on health status only included community-dwelling people. The data pointed out the frequency from geriatric syndromes, allowing us to detect the main problems to be addressed which are: cognitive decline and dementia, falls, pain and its undertreatment, inadequate pharmacological treatment: overuse of psychoactive drugs and underuse of calcium and vitamin D, physical restraints, malnutrition, dehydratation and high dependency. These results are consistent with the results obtained in other countries.

In fact, our current research already covers many of these areas and we are currently working on fall prevention, malnutrition, dehydratation and cognition in Nursing Homes. We are also involved in professional networks within Spain focused on: fall prevention, sarcopenia management, person-centred dementia care and reduction of physical restraints. Further on, we identify as relevant topic to implement disability prevention in Nursing Homes addressing frailty and sarcopenia.

Research on the Models of care

Older people's movement, experts on the gerontological field and also the Spanish welfare and health administrations are interested in studying and implementing news models of long-term care. Our institute is working on this field with the main aim to define a new model which should guarantee a

better quality of life and be based on the person-centred care. The models of housing established in the Nord of Europe, which are being expanded around the world, are seen as an example. However, since the existing options of long-term care nowadays in Spain are far away from this model, many questions arise:

How could we adapt the actual model to the different models of housing? How could we guarantee adequate health assistance in the new model when we have still shortcomings in the actual nursing homes? What about the costs of the new model and the characteristics of the human resources which differ a lot from our current model? How can we organize the especial care units for Alzheimer diseases in this model? Thus, how can we change our places of care, our practice of care and, in summary, our culture of care within our culture?

These questions are certainly relevant topics to be addressed by research as well.

Research on clinical management and quality of care

There is a high agreement on the multidisciplinarity of the team as basic to provide global care. Some clinical management instruments such as the RAI System (2) have been developed to conduct a multidimensional evaluation and interventions. Following this principle, in 2000 the Health department of Catalonia established a Minimum Data Set (3) based in the Resident Assessment Instrument as a compulsory tool in long-term care. This methodology allows obtaining the RUG classification, which evaluates the case-mix and gives support to the clinical management. Furthermore, the RUG classification obtained since 2001 allows following the case-mix evolution in these facilities. Moreover, the quality-oriented management in the provided services requires establishing on-going evaluation strategies to introduce progressive changes in the model. This policy has been followed as well by the Health Department of Catalonia, which has established quality of care indicators (4).

Practicing clinical research on nursing homes

Our experience on nursing homes allows us to draw some limitations and possibilities of doing research in these units. The work overload of the professionals is a main barrier which difficult them carrying out research besides their usual tasks. Further on, most of the nursing home professionals are used to work with data for the clinical practice, which differs from collecting data for research. We have also experienced some opportunities. For instance, when professionals conduct the assessments and they receive training before, they can be motivated and trained at the same time and, further more, their experience doing research may improve daily care in long-term care facilities.

In summary, research in long-term care is urgently needed to ameliorate the health care provided, to change the actual model into different housing models which offers person-centred care and so guarantees a better quality of life, to adapt clinical management to specific needs and to improve the quality of care. However, although carrying on clinical research in long-term care faced difficulties due to the training and disadvantageous working conditions of the professionals, it also provides paths to improve the quality of care and thus the quality of life. 1. The institutionalized people health survey of Catalonia: Comorbidity and disability in nursing homes and long term care hospital units. X. Rojano*, P. Brugulat, L. Coll, E. Séculi, A. Salvà (Barcelona, Spain). Poster presented at the XIXth IAGG World Congress, Paris, July 2009. 2. Development of the nursing home Resident Assessment Instrument in the USA. Hawes C, Morris JN, Phillips CD, Fries BE, Murphy K, Mor V. Age Ageing. 1997 Sep;26 Suppl 2:19-25. Review. 3 . Registre del Conjunt Mínim Bàsic de Dades. Manual de notificació. Recursos sociosanitaris. Servei Català de la Salut. Generalitat de Catalunya. 2003. 4. Serveis Sociosanitaris: Indicadors per mesurar els criteris de qualitat de l'atenció al pacient i la família. Generalitat de Catalunya. Planificació i avaluació sanitàries Pla Director Sociosanitari. 2006.

NURSING HOMES IN CHINA: NOW AND THE FUTURE, *B.R. Dong, S.Y. Wu (China)*

China is facing growing challenges from the increasing elderly population, the number of elderly who require care is growing, "4-2-1" family structure and "empty nesters" exacerbate the burden of care. The existing nursing homes are far from meeting the demand. However, two extremes exit: overcrowding and low occupancy because of cost, facilities and services. There is a severe shortage and instability for caregiver. The majority of caregivers have the low education, they receive little training in elder care. No matter how difficult it is reform is essential and urgent, The next 25 years will be key for Chinese government preparing to deal with China's aging society, and that strategies must be developed to improve laws and regulations for care elderly, and encourage private and foreign investors to participate in the nursing home business. Establishing a complete set of laws and regulations, exploring the most appropriate care model, improving care service, professional training and recruiting volunteers are challenges to China in future.

Unprecedented population aging and dilemma in China

China is running into the aging society, the speed and extent of aging beyond imagination. By the end of 2009, the number of people over 60 years old exceeded 167 million, accounting for 12.5 percent of the total population. By 2020, that number will increase to 248 million, taking up 17 percent of the country's population (1). China's octogenarian elderly population is more than 18.06 million, the rate of growth is 5.4%, this means that there will be an increase of 500 000 people over age 80 every year.

China is facing these dilemmas: the rapid aging of population, uncovered elderly by social security systems, the gradual reduction of labor force and the rapid increased need of care for the elderly with chronic disease and disability. There is also an accelerated migration from rural to urban for young people thus, increasing the number of the empty nest elderly.

There are also growing demands for upgraded welfare facilities and the care services lagging behind the development.

The heavy burden of long-term care in China

Recently, an online survey by www.people.com.cn showed that care of the elderly ranked first, for the first time, among the issues raised by citizens (2). The size of the working-age population is shrinking. The elderly-support ratio—the working-age adult (ages 15 to 64) per number of elderly (age 65 and above) is projected to decline drastically from 9 persons to 2.5 persons by 2050 (3).

Traditional Chinese culture has great respect for elders, and for a long time, the elderly were taken care of by younger family members. However, the informal care system is getting weaker because of the one-child policy that is leading to a '4-2-1' family structure, for every one couple, there are four or more older family members who may eventually need to be cared for. In the future, fewer children will be available to care for their ageing parents.

The massive migration of young people from domestic to foreign countries or from rural to urban is leading to a rise of "empty nesters". China has at least 23.4 million "empty nesters" and the number is growing, it is estimated it will reach 90 percent by 2012, (4) and this situation is more serious in rural areas.

Several large-scale national surveys show that more than 32.50 million elderly people need different forms of care services, and more than 5.8 percent of the urban elderly said they are willing to live in nursing homes. But, there are 39 and 546 nursing homes in urban and rural areas of China respectively in 2006, with a total 1.497 million beds, which is about 0.84% of the total elderly population, much lower than 5% of international level. Therefore, there is a huge gap in the market of nursing homes and institutions.

The status of nursing home in China

Forms of the nursing home

The nursing home in China is mainly divided into three types: the government-run social welfare institution and apartments for the elderly (managed by provincial, municipal and district government), the collective-run nursing home in rural townships and lastly private nursing home, with the first two mainly accept the elderly with no children and no other means of support.

Occupancy rate and influence factors

Our survey of 10 nursing homes (out of 110) suggests that the size of nursing home in Chengdu (the capital of Sichuan province) varies from 20 to 300 beds, 58.7% elderly in nursing home are over 80 years old, the occupancy rate of government-run and collective-run nursing home are 92.7%, while that of private nursing home is range from 30% to70%. At a government-run nursing home in Guangzhou (in south of China), the 1,100 beds are almost fully occupied and more than 100 people are on a wait list to get in, with inquiries coming in every day. The main factors influencing the elderly to select nursing home are cost (50%), quality of care (24%), living conditions (18%) and the distance from home (8%). The private nursing home has a low occupy rate for two very different reasons; because of excessive luxury and high cost or inadequate condition due to a lack of funds and policies. Table 1 shows the basic demographic information for the elderly in nursing homes in Chengdu.

Provision of services

The service provision varies from urban to rural areas and from developed to undeveloped area. In ten nursing homes of our survey, five refuse to accept elderly with dementia, three refuse to take those who are completely dependent. The cost varies by types and levels of care in each nursing home, charged from 500RMB ($73) to 2,240RMB ($328) per month in Chengdu of southwest China. The basic service provides personal care, room cleaning, meals, laundry, and basic medical care. The activities mainly include watching TV, playing mahjong and chess, the variety of programs depending on the health and interests of the elderly was not unavailable. The facility is old and poor. The quality standard for care, including standard setting, assessment, and monitoring is still inadequate, with 90% nursing homes in China do not provided rehabilitation therapy and volunteer service.

Severe shortage and instability of caregiver

Facing more than 18 million Chinese over 80 and 169 million people who are over 60, there are only 20,000 qualified elderly caretakers, there is a urgent need of 10 million professionals (5). The teams of care staff have a high mobility because of low income, long working hours and insufficient knowledge. The majority of caregivers in nursing home were formerly farmers (58.1%), laid-off workers or retired workers (38.7%), 60 caregivers from 10 institutions in our study show that illiteracy is 19.4%, primary school is 56.5% and junior middle school is 22.6%. Most care staff receives little training in elder care.

Future development strategies in China

The rise in the aging population has pushed China to work at building a comprehensive and efficient national social security system to support the elderly in both urban and rural areas. To provide basic care for this disadvantaged group, the government has given monthly old allowance to the elderly over 80 years old and further promotes the nursing allowance system across the nation.

China's development of elderly care will undoubtedly be based upon in-home care. In addition to the overwhelming percentage of elderly who prefer to be in their own home rather than a nursing home, the government has already begun to dedicate its attention and resources to developing this industry,

and encourage private and foreign investors to participate in the nursing home business.

No matter how difficult it is reform is essential and urgent. The Ministry of Civil Affairs has made plans to promote daycare centers for the elderly in communities across the country and provide professional training programs to care staff.

In view of China's huge elderly population and inadequate financial resources, the developments of various forms of elderly services are upcoming trends, like as home-visit care, day care, and community-based care. The community services including hostels, emergency calls, hotlines, BP calls, bell for help, welfare houses, rehabilitation houses, nursing homes, day care center, and entertainment activity centers are being gradually popularized in different city of China.

Thoughts and Suggestions on expanding China's care service for elderly

(1) Chinese government should establish a complete set of laws and regulations on developing and improving care service for elderly and present a systematic and integrated policy system for management and operation of nursing home.

(2) The regulations and standard of nursing homes needs to be seriously planned and implemented, and an evidence-based evaluation system needs to be developed. Government should perform inspections regularly.

(3) Professional training needs to be organized. The doctors and nurses working in nursing homes should be trained in general medicine, rehabilitation and community nursing respectively, focusing on elderly care. For medical students, general medicine, rehabilitation, and community care should be included in the core curriculum, and encourage younger doctors or nurses to work in nursing homes. For caregivers, training programs should improve caregiver's skills include the physical care and mental care should be given if needed, with their own interests protected.

(4) Volunteers must be recruited, oriented, and supervised to be used effectively in nursing homes. Establish and improve the management model and operation mechanism of voluntary services in nursing home, promote the participation consciousness of citizens and enhance citizens' acceptance of volunteers.

We believe that care services for elderly in China will develop at a high speed. By the year 2020, although, the family continues to provide the majority of care for the elderly and disabled, considering the importance of the traditional family in China and the presence of the '4–2–1' family structure, there will be a painful transition from predominantly family care to community care for the elderly. Fortunately, central and local governments have become aware of this imminent transition.

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PAIN MANAGEMENT IN NURSING HOMES AS A MARKER OF QUALITY OF CARE,

S. Franzoni, M. Trabucchi (Italy)

In long-term care facilities the prevalence of chronic pain ranges as high as 83% and 40% of residents with cancer and 25% without cancer are not treated with analgesics, even though they may be experiencing pain on a daily basis. Another important phenomenon in nursing home is that both acute and chronic pain is more underrecognized and undertreated in patients with cognitive impairment.

Nevertheless specific analgesic strategies in geriatric setting, as reported in American Geriatrics Society (1998, 2002, 2009) and American Medical Directors Association (1999) Clinical Practice Guidelines, today pain management is rarely approached in the real world of nursing home with a formalized pain assessment and appropriate use of pharmacologic agents and non pharmacologic interventions.

In front of this data, today, the care of pain (relief or analgesia and not complete pain ablation or anesthesia) can represent one of the most important domain to improve the quality of life in nursing home, because it may reduce behavioural disturbances (emotional stress, frustration, increased irritability, anger, anxiety, agitation, depression, social withdrawal, disturbed sleep patterns, diminished appetite and/or weight loss) and enhance functional.

Literature on pain management in long-term care settings show that pain is poorly assessed, without adopting a specific standardized tool. The problem is not the lack of scales for evaluation pain, but the "use of scores". It is necessary a strong agreement among nursing staff and physicians to translate the information of assessment in an analgesic therapy. Scores do not automatically indicate a level of pain while respecting the report of communicative patient, the pain intensity need a careful interpretation according to behavioural, mood, functional status and level of comorbidity. Assessment of the cognitive status is crucial to learn the most appropriate pain assessment tools. In non-communicative demented patients the measure of pain severity through observational scales is more difficult and the use of an "analgesic trial" helps to validate if potential behavioural indicators of pain respond to analgesic treatment.

When patient with pain is identified is necessary to adopt a treatment plan based not on ''standard'' and at low dosages analgesics at-needed dosing, but on polymodal and polypharmacy, at timespecific dosing to prevent drug-seeking behaviour.

The adverse event profile varies greatly between opioids. Agents may be used if have a good tolerability profile (especially regarding CNS and gastrointestinal effects) and are as safe as possible in overdose. Slow dose titration helps to

reduce the incidence of typical initial adverse events (such as delirium, falls, nausea and vomiting). The widespread use of psychotropic drugs in nursing home patient is a significant limitation to analgesic care with opioids. In the general weakness of scientific data about care of pain in advanced age, some evidence show a low prevalence of side effects with low or medium dose long-term opioid therapy associated with benzodiazepines and/or antidepressants.

In this respect, we examined the results of short analgesic training of nurses on care of pain in 4 nursing homes, located in Trento city and hinterland (northern Italy). The education consisted in 4 hours dedicated to the etiology, clinical aspects, signs and specific tool (Non-Communicative Patients' Pain Assessment Instrument - NOPPAIN) to detect pain in non-communicative patients. The study was conducted in 102 institutionalized patients (86% F) with Mini-Mental State Examination – MMSE - score <19/30 (MMSE 4+6.2). In the previous year these patients have been examined without standardized pain instrument and differently treated with analgesic drugs according to cognitive deterioration (prevalence of analgesic drug for year: MMSE 0-6= 49% vs MMSE 7-12= 67% vs MMSE 13-19= 86%). The principal analgesic drugs were NSAID (44%), acetaminophen (23%) and opioids (codeine and tramadolo 21%). After training, at the start of the study the prevalence of pain resulted lower in patients with severe dementia (MMSE 0-6= 53%; MMSE 7-12= 67%; MMSE 13-19= 77%), while after 1 month of controlled daily application of the NOPPAIN scale the percentage of patients with pain was the same in the different group of patients. In the 3 subsequent months the nursing homes adopted methods to assess pain, but at an unexpected daily follow-up, the attitude (90% uses NOPPAIN every days) and ability to detect the pain in patients with severe dementia resulted preserved (MMSE 0-6= 32% vs MMSE 7-12= 33% vs MMSE 13-19= 36%). The global reduction of prevalence of pain (20%) was due to improvement and quality of analgesic therapy. The physician stimulated and supported by daily NOPPAIN reports used more analgesic drugs, particularly opioids, although the "fear" of their side effects is more current for patients with severe dementia (prevalence of analgesic drug for one day: MMSE 0- 6= 16%, MMSE 7-12= 33%, MMSE 13-19= 36%). The patients with pain had more behavioural and psychological symptoms (BPSD) than subjects without pain (registered at the first week of month-study through the Neuropsychiatric Inventory - NPI: 13.4+16.4 vs 7+8.5) and particularly in severe dementia (MMSE 0-6, NPI: 14.9+17.9 vs 7.4+8.4). At the last week of study BPSD resulted in all patients lower than at the first one (NPI: 9.3+16.6 vs 6+10.7).

These results are positive if we take into account the low costs (personal and personnel and money) of nurses' training. Some suggestion can be proposed to improve the care the pain in nursing home.

First, it is always necessary an etiological diagnosis of pain; in nursing home the focus on pain treatment is not mere palliation, but it is directed at the prevention based on pain aetiology (pressure sores, contractures, iatrogenic). Neuropathic pain such as allodynia, hyperalgesia and hyperpathia is difficult to assess in patient with cognitive impairment and cause an underreported incidence of neuropathic pain.

Second, the training of nurses could be improved using videotapes that show the different behavioural disorders and help to measure the level of pain intensity. Moreover, in long-term care facilities to develop the communication and agreement among the staff it would be useful the adoption of a weekly schedule with day by day data about intensity of pain, dosage and type of analgesic drugs, side effects and psychotropic drugs. With this schedule nurses and physicians may early detect the effect of analgesic therapy.

At the last, it is necessary an involvement of the nursing home establishment and family caregiver. The directors of nursing home have a crucial role to reduce pain in institutionalized patients, not only for supporting economic aspects of team educational process, but for defining pain like a relevant and feasible aim to improve quality of life. As much as the limitation of pressure sores, falls and use of restraints, the reduction of pain could be an indicator of the quality of long-term facilities. At the same time the role of family caregivers on care of pain may be very important to meet this aim and might be included in the management program of any nursing home.

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INTEGRATION OF PALLIATIVE CARE IN U.S. NURSING HOMES, *D. Swagerty (USA)*

More than 25% of Americans now die in a nursing home and there is considerable evidence that long term care residents do not receive optimal end-of-life care (1). Fortunately, internal palliative care programs and contracted hospice services are being used more frequently in this long term care setting. The interdisciplinary support of the palliative care or hospice team can be invaluable in supporting the usual nursing home care at a time when staff, family members and the patient are facing the increased and urgent needs associated with the dying process (2).

Benefits of Palliative Care in Long Term Care Setting

Many healthcare providers, nursing home residents, and the families of nursing home residents are becoming aware that a goal of comfort is more satisfying and reasonable for nursing

home residents, than are aggressive life-prolonging goals (3). A well defined and resourced palliative care program can make it much easier for nursing home staff, physicians, and other providers to give comprehensive end-of-life care to those residents with life-limiting and terminal conditions. A palliative care program in the nursing home could take the form of either a specific internal program developed and maintained by the nursing home or by contracting with one or more community-based hospices.

Like most patients at the end of their life, nursing home residents prefer to remain in their usual setting. This arrangement supports the natural dying process in the nursing home. The many advantages of a focused palliative care program for the near terminal and terminally-ill nursing home resident are listed in Table 1. With the long standing presence of hospices in U.S. nursing homes, all of these advantages have been demonstrated as resulting from their care.

Table 1
Advantages of Focused Palliative Care for the Near Terminal and Terminally Ill Nursing Home Resident

· Better Pain Assessment and Management
· Lower Rates of Inappropriate Medication Usage
· Less Physical Restraints
· Resident Kept in his/her Own Environment
· Services Provided Beyond those Usually Offered in Nursing Homes
· Medical Goal becomes Pain Relief and Symptom Control.
· Management of the Residents Increasing Hygienic Needs.
· End of Life Education for the Family and for the Nursing Home Staff.
· Bereavement Support for the Family, and the Nursing Home Staff
· Prolonged Visits for Compassionate Listening and Companionship.
· Providing Medications and Medical Supplies Related to the Terminal Diagnosis.
· Spiritual Support.
· Limiting Hospitalizations and Life-Prolonging Therapies.
· Greater Satisfaction of Surviving Family with the Nursing Home.
· Education of the Nursing Home Staff on End-of-Life Care.

Some nursing homes are able to provide comprehensive palliative care that includes services that are equivalent to hospice care. However, nursing homes vary widely in terms of size, financial status, and population and not all are able to develop comprehensive palliative care programs. When residents reside in nursing homes without an active palliative care service, community hospices are often able to identify multiple unmet palliative care needs. In addition, there is good evidence that nursing home residents receiving hospice services are more likely to have good pain assessment and management, have lower rates of inappropriate medication usage, and are less likely to have physical restraints. Families also perceive that hospice improves nursing home care (4). To date, internal palliative care programs in nursing homes are less wide spread and well established then hospices. The evidence has yet to be developed that internal palliative programs can offer the same end-of-life benefits to nursing home residents and their families currently provided by hospices.

Barriers to Palliative Care in Long Term Care

Government policy and reimbursement in the U.S. emphasizes rehabilitation and restoration of function as the goals of nursing home care. Yet, at the end-of-life, all indicators of successful restoration are going to fail. Additionally, nursing homes are one of the most heavily regulated U.S. industries. Many survey domains used to measure quality in nursing homes, such as weight loss, anorexia, functional decline, and increased usage of opioids and antipsychotic medication, are common and appropriate clinical presentations in palliative care. Therefore, addressing these clinical conditions as part of a palliative care approach might be perceived as indicating poor nursing home care unless goal setting and documentation is explicit. It is imperative to recognize and avoid this "clash of philosophies" in order to advance quality end-of-life care in nursing homes.

In the U.S., reimbursement for end-of-life care has favored the growth of community-based hospices. To their credit, hospices have developed considerable expertise in delivering quality end-of-life care to terminal patients with good evidence that measurable outcomes are improved when hospice is involved in the care of terminally-ill nursing home residents. However, there is still a significant gulf between the cultures of hospices and nursing homes.

A variety of financial disincentives create barriers to referral of nursing home residents for hospice services. These barriers can make hospice an undesirable choice for residents and their families, as well as may make nursing homes less likely to refer. This is especially true for residents being admitted from the hospital after a sentential health event, some of which may indicate a lifelimiting or terminal prognosis. The Skilled Nursing Home Benefit is more affordable for residents than paying privately for room and board care in the nursing home under the Medicare Hospice Benefit. In addition, when a resident elects the Medicare Hospice Benefit rather than the Skilled Nursing Home Benefit, the nursing home receives a lower reimbursement rate through private payment from the resident or Medicaid. Together, these factors create a substantial disincentive to hospice enrollment for the nursing home, as well as the resident and their family. These and related reimbursement systems need to be reevaluated and redesigned to eliminate inappropriate barriers to hospice access. Furthermore, nursing homes should be able to facilitate this choice without the concern about financial risk or losses.

Other common barriers to high quality end-of-life care in U.S. nursing homes include; 1) many facilities do not have established procedures for ensuring that appropriate residents receive palliative care services, 2) high nursing home staff turn-over and insufficient staffing, 3) limited staff training, and 4)

most residents have multiple co-morbidities, including progressive dementia in more than half. This makes life expectancy estimates much more difficult. Nursing home residents with dementia are more likely to be referred later than residents with a cancer diagnosis, which often has a much more predictable life expectancy (5-7).

Overcoming the Barriers

Ideally, internal palliative care programs in nursing homes would offer the best hope for wider implementation of quality end-of-care in this setting by becoming integral to the care-planning for every resident. However, reimbursement for nursing homes does not favor end-of-life care nor are most facilities currently equipped with the clinical expertise and administrative infrastructure needed to fully implement this type of care for those residents at the end of their lives. These two primary barriers would need to be first addressed before quality end-of-life care becomes part of the "fabric" of U.S. nursing home care.

Methods to meanifully merge quality end-of -life into the usual nursing home services must be sought in order to improve medical and quality of life outcomes, as well as family and nursing home resident satisfaction. First, both nursing homes and hospices must be receptive to education and cross-cultural exchange to offer the high quality end-of-life care benefits desired by nursing home residents and their families.

In the short-term, there are many impactful methods to overcome the barriers to quality end-of-life care for nursing home residents through the use of hospice; including, 1) improved communication between patients, physicians, families, nursing home staff, and hospice professionals, 2) support for advanced care planning, 3) explicit goal setting, 4) proper documentation by the hospice and nursing homes, 5) appropriate, earlier referrals to hospice, 6) education of hospice and nursing home health professionals, residents, and families.

The long term solution to providing quality end-of life care to nursing home residents is though self-directed programming by nursing homes. However, adequate financial resources must be provided both external and internal to the facility. For example, the Medicare Hospice Benefit and the Skilled Nursing Home Benefit must be placed on financial parity for residents and nursing homes for the care of residents with life-limiting or terminal conditions. This decision must be made on the basis of clinical benefits rather than financial ones. Developing and maintaining internal palliative care nursing home programs will then be contingent on facilities possessing the required clinical and administrative expertise required to deliver quality end-of-life resident care given the many competing demands on their staff.

Conclusion

There is good evidence that end-of-life care for many U.S. nursing home residents is suboptimal. It would be ideal for nursing homes to provide palliative care as part of a seamless continuum of care from restorative care and rehabilitation, through long term and dementia care, to end-of-life care as dictated by the needs of the resident. However, the U.S. reimbursement and clinical care systems have favored supplemental hospice services as an addition to the usual nursing home services for nursing home residents with life-limiting and terminal conditions.

Barriers to hospice providers providing end-of-life care in the nursing home include the emphasis upon restoration and rehabilitation by the long term care survey process and funding sources, lack of communication between the nursing home and hospice providers, and late referrals to hospice due to the difficulty in predicting life expectancy for many nursing home residents. Improved communication, goal setting, documentation, and education can overcome these barriers in the short term. The long term solution for providing quality end-of-care in nursing homes is improved, focused and direct reimbursement to the facilities for this type of care. Clinical and administrative expertise in providing comprehensive palliative care would then need to be developed and maintained on a wide spread basis by the facilities.

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LONG TERM CARE MEDICAL EDUCATION IN THE US: TRAINING MEDICAL STUDENTS, RESIDENT PHYSICIANS, AND PRACTICING PHYSICIANS, *D. Swagerty (USA)*

While the breadth and depth of geriatric medical education in the United States has expanded greatly over the last 25 years, the specific training of medical professionals in long term care medicine has not undergone as much growth or uniformity. Most medical students and primary care resident physicians receive some exposure to long term care medicine, but this aspect of geriatric medical education is still variable across schools of medicine and postgraduate primary care residency programs. The most impactful long term care medical education training has occurred through continuing education courses of practicing physicians. In particular, the American Medical Directors Association (AMDA) has taken the lead in training these already experienced medical professionals in the identified knowledge and skills to be an effective long term care physician.

AMDA is a national professional association of medical directors, attending physicians, and other professionals practicing long term care medicine (LTC) committed to the

continuous improvement of patient care. Currently, all long-term care facilities are required to have a physician identified as a medical director. Many medical directors serve in a variety of settings across the long term care continuum; including, skilled nursing facilities, assisted living, hospice care, subacute/post-acute care, home care, long term care hospitals/long term acute care hospitals, and continuing care retirement communities (CCRCs).

AMDA and its affiliates – the AMDA Foundation (AMDA-F) and AMDA Certification Program (AMDCP) - conduct several ongoing programs which provides a professional development continuum in long term care medicine as shown in Table 1and discussed in the following section.

Table 1
AMDA Long Term Care Medicine Professional Development Continuum

- The AMDA Foundation's Futures Program was developed to bring new physicians into the field by providing an intensive learning experience for medical residents and fellows in internal medicine, geriatrics, and family medicine, highlighting rewarding career opportunities available in long term care.
- The AMDA Core Curriculum on Medical Direction (Core Curriculum) guides physicians through 20 critical areas of long term care management. Each topic builds on information shared and interactive exercises to create a comprehensive and cohesive picture of medical direction in long term care.
- The Certified Medical Director in Long Term Care Program was created to professionalize the field of medical direction. The Certified Medical Director (CMD) program recognizes the dual clinical and managerial roles of the medical director. Certification requires indicators of competence in clinical medicine and medical management in long term care.

American Medical Directors Association (AMDA) Long Term Care Medicine Professional Development Continuum

Futures Program

The AMDA Foundation Futures Program was created to address the critical shortage of American physicians serving frail elders in long term care settings by increasing the number of primary care residents and fellows interested in long term care practice as medical directors, attending physicians, and long term care researchers. The Futures Program is the Foundation's central focus in its mission to educate and inspire current and future long term care professionals.

According to the Institute of Medicine's (IOM) 2008 report, Retooling for an Aging America, the number of American older adults will nearly double between the years 2005 and 2030. One of the report's key findings is that as the population of older adults grows to approximately 20 percent of the U.S. population, the health care system will be inadequate to meet societal needs. The numbers in the workforce will be too small and they will not be prepared to meet the needs of an aging population.

The IOM analyzed data from the Association of Directors of Geriatric Academic Programs (ADGAP) and the Alliance for Aging Research and found "there is currently a shortage of approximately 12,000 geriatricians; by 2030 the shortage will be about 28,000. By 2025, there is projected to be an overall shortage of 100,000 physicians." Underscoring the seriousness of the problem, the IOM report noted that "as of January 2007, 23.3 percent of all active physicians were 60 or older, and by 2020 almost half of all registered nurses are expected to be over age 50."

The Futures Program is one way to address the imperatives in the IOM report. Indeed, many past participants become medical directors of long term care facilities and set the protocols and care processes within the facilities. Several past participants are now leaders in the research arena and others serve as leaders within AMDA and the AMDA Foundation. Since its inception in 2000, the program has become a highly sought after experience that is very desirable for any primary care resident physician or geriatric medicine fellow considering working in long term care. Almost 500 primary care residents and geriatric fellows have participated in the Futures Program.

The Futures Program identifies those primary care resident physicians and geriatric medicine fellows who are interested in long term care and provides them with an intensive training program to help them assess career opportunities in long term care medicine. Attendees have the opportunity to hear from long term care physicians on a variety of topics pertinent to a long term care as a career path. Sessions span a general overview of long term care practice, practical approaches to LTC management, quality improvement and clinical practice guidelines, as well as risk management.

The Futures Program is held immediately prior to AMDA's annual symposium. Attendees have the opportunity to participate in symposia workshops, receiving invaluable educational opportunities in the area of long term care practice. As the only national program that provides information and guidance on how to pursue a career in long term care, the Futures Program also provides participants with invaluable networking opportunities.

Most recently, the Foundation introduced a new and successful mentoring component to the Futures Program. Futures participants are now partnered with an active and involved AMDA member who mentors the participant, sharing experiences and wisdom. Mentees learn the value of becoming a Certified Medical Director, what it is like to practice in various LTC settings, understanding roles and responsibilities of medical directors, guidance in career planning, and other professional and personal development mentoring.

Futures participants are chosen from a competitive selection process and they receive admission to the Futures Program, registration to AMDA's Long Term Care Medicine annual symposium, AMDA membership for one year, and a monthly subscription to the Journal of the American Medical Directors Association (JAMDA). The AMDA Mentoring Program also

matches Futures participants with medical directors working in the region where they are pursuing their postgraduate training or they intend to work after completion of their training. Program participants consistently indicate that the Futures Program meets an important need for them that they do not receive in their individual residency and fellowship training programs, including, mentoring by LTC medicine leaders, professional networking and the encouragement of intellectual independence.

AMDA Core Curriculum on Medical Direction in Long Term Care

This week-long continuing education course is tailored to the needs of practicing physicians who practice in any long tem care setting or combination of settings across the long term care continuum; including, skilled nursing facilities, assisted living, continuing care retirement communities, hospice, and home care. Geriatric fellows in training who are considering the inclusion of LTC medical direction in their future medical practices find this course to be a beneficial introduction to management requirements for long term care. The goal is to create a stronger sense of the leadership role of the long term care medical director and to provide opportunities to develop skills and interact with peers. The objectives of the course are listed in Table 2.

Table 2
AMDA Core Curriculum on Medical Direction in Long Term Care Course Objectives

- Develop practical skills needed to fulfill the role and responsibilities of the medical director.
- Identify the unique aspects of the long term care environment that impact the medical director's job.
- Describe the organizational responsibilities and dynamics of the medical director and the interdisciplinary team.
- Develop communication skills to deal with responsibilities for the interdisciplinary team, residents, and their families.
- Explain the resident care responsibilities of the medical director, including emergency care, quality management, family systems, and ethical considerations.
- Enhance leadership skills and team building towards a stronger role for the medical director with the interdisciplinary team.
- Develop human resource skills to deal with difficult situations and improve personal effectiveness in this area.

Certified Medical Director in Long Term Care (AMDA CMD) Program

The American Medical Directors Certification Program (AMDCP), an independent affiliate of AMDA, recognizes and advances physician leadership and excellence in medical direction throughout the long term care continuum through certification, thereby enhancing quality of care. The certification program was developed over several years of through research, surveys, and several consensus conferences to identify essential skills and knowledge to serve as an effective long term care medical director.

Since 1996, the program has been administered by the American Medical Directors Certification Program (AMDCP). Since the program's inception, more than 2,500 physician medical directors have received the AMDA CMD designation. The Certified Medical Director (CMD) in long term care recognizes the dual clinical and managerial roles of the medical director. The CMD credential reinforces the leadership role of the medical director in providing quality care and provides an indicator of a long term care medical director's professional competence to long term care providers, government, quality assurance agencies, consumers, and the general public.

The certification process is based on completing geriatric medical clinical training and management education, as well as long term care practice experience. Both AMDA members and non-member physicians who currently serve as medical directors or associate medical director, in one or more long term care facility/setting are eligible to apply if they meet each of the criteria listed in Table 3.

Table 3
Certified Medical Director in Long Term Care (AMDA CMD) Program Certification Steps

Primary Clinical Qualifications:
- Basic Postgraduate Education and LTC Clinical Experience: Completion of a U.S. Accreditation Council for Graduate Medical Education or American Osteopathic Association accredited post-graduate training program in any specialty, or a Canadian Royal College of Physicians and Surgeons or College of Family Physicians accredited post-graduate training program and complete two years of clinical practice in long term care
- Current Licensure: Hold a current, unrestricted, state license as an M.D. or D.O. in the U.S. or an equivalent license to practice medicine in Canada OR
- Advanced Postgraduate Education in Geriatrics and LTC Clinical Experiences: Completion of a geriatric medicine fellowship or hold a Certificate of Added Qualifications in Geriatrics. This track does not require a separate completion on clinical experience in long term care, as this training is provided as part of a geriatric medicine fellowship or Certificate of Added Qualifications in Geriatrics
- Current Licensure: Hold a current, unrestricted, state license as an M.D. or D.O. in the U.S. or an equivalent license to practice medicine in Canada

Specific LTC Medical Direction Qualifications:
- Medical Direction Experience: Spend a minimum of 8 hours each month in service as a medical director in a long term care setting.
- Medical Direction Education: Complete the one week live course - AMDA Core Curriculum on Medical Direction

Recertification: Required every six years.

Value of CMD Certification

A 2009 study published in the Journal of the American Medical Directors Association (JAMDA) found that having an AMDA Certified Medical Director (CMD) contributes positively to a nursing home's quality of care. Analysis of data

showed that quality of care scores represented a 15% improvement for facilities with Certified Medical Directors (CMDs). The data also addresses how other factors – including facility size, not-for-profit status, and higher registered nurse (RN) hours per patient day – relate to the presence of a CMD to impact the quality of care in nursing homes (Rowland 2009).

The data from this study may have policy implications in all of long-term care. Because the certified medical director designation indicates a minimum level of experience and education in medical director management and clinical geriatric medicine, it suggests that every long-term facility and program should have a certified medical director or the equivalent.

Summary

The experience of training of medical professionals in long term care medicine in the United States has shown that there is a urgent need to focus attention and resources across the professional development continuum to provide for the present population of older adults in long term care settings, as well as prepare for the anticipated significant growth in this area of medical practice. All medical students, primary care resident physicians, and geriatric medicine fellows must receive specific long term care medical training to meet the challenges of caring for an increasing vulnerable population of older adults. Dissemination of impactful medical education and training for all practicing physicians in the long term care continuum is also a pressing health care need.

The two greatest current challenges for long term care medical education will be developing meaniful competencies for practicing in the long term care continuum and identifying the resources necessary to make these competency-based criteria a reality. Addressing these important issues by an international panel of long term care experts will be an exciting opportunity to advance the agenda of global quality long term medical care. 1. IOM. Retooling for an Aging America Building the Health Care Workforce. Committee on the Future Health Care Workforce for Older Americans Board on Health Care Services. Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C., 2008; 2. Rowland F, Cowles M, Dickstein C, Katz P. Impact of medical director certification on nursing home quality of care. J Am Med Dir Assoc. 2009; 10: 431-435.

PROMOTING EVIDENCE INFORMED IMPROVEMENTS IN CARE HOMES: NURSING PERSPECTIVES, *D. Tolson (United Kingdom)*

Introduction

Achievement of evidence based practice is seen by many as pivotal to delivering quality services with demonstrably high standards. In the mid 1990's evidence based practice was defined in terms of practitioner decision making that involves the explicit and judicious use of the best available evidence in determining the optimal care for individual patients. The early emphasis on hierarchies of research evidence with randomised controlled trials as gold standard has shifted towards more inclusive views of evidence that recognise practitioner tacit knowledge and patient preference and their application in practice (1). Promoting a culture where evidence is generated, synthesised and applied is now the contemporary and accepted way forward.

Although evidence informed practice has become the healthcare policy mantra evidence use in practice remains patchy and there are numerous exemplars from care homes, where the influence of evidence is unclear or at worst absent. The evidence practice gap manifests in the failure to implement new approaches and eliminate practices such as the contentious but persistent practice of restraint.

Opponents of evidence based nursing question its viability given the well documented implementation challenges, but it is however difficult to argue against the quest to promote the most effective care and the cessation of practices which are unsafe, ineffective (2) or breach human rights.

Admission to a care home is usually triggered by complex and enduring health needs, multiple pathology and increasing dependency. A recent trend in research has been to focus on psychosocial aspects including the transitions involved in becoming a cared for resident.

The assertion in this paper is that evidence informed improvements to optimise nursing management of prevalent later life conditions must be central to the care home development and research agenda. This requires research not only about condition management but also on effective implementation methods focussed on working with older people who live within care homes. Balance is required to ensure that we advance knowledge about these clinical dimensions of gerontological nursing practice in tandem with advancing conceptual dimensions of care and the promotion of quality of life.

Finding Focus

There is growing recognition among implementation scientists that evidence use in practice is highly contingent on contextually situated decision making (2). Evidence translation processes and the relationship between evidence use, care experiences, quality of life and overall standards within care homes are poorly understood.

It is beyond the scope of this paper to detail condition specific research priorities but it is important to note increasing calls for nurses who work with older people to demonstrate qualities in the experience of care and in delivering clinical outcomes. This creates momentum for renewed consideration of the meaning of quality nursing within care homes which could extend to the development of nursing sensitive indicators. For example Griffiths et al (3) persuasively argue that evidence-based indicators which measure outcomes delivered by nurses have the potential to capture trends, allow performance comparisons and targeted improvement

interventions. Four promising evidence-based indicators to measure the outcomes delivered by nurses within acute care were identified by the English Taskforce as;

1. Patient safety indicators (failure to rescue associated with preventable deaths, healthcare-associated infections, falls, pressure ulcers).
2. Patient experiences of compassionate care (an important outcome in its own right).
3. Staffing and skill mix indicators linked to patient outcomes.
4. Process indicators.
   (3).

The arrival of nursing metrics, signals the beginning of a new era where the nursing contribution can be ascertained in ways that bring together measures of effectiveness, safety and compassion. With global ageing and the predicted increase in the numbers of care home residents it is timely to invest in the development of nursing metrics appropriate to the care home environment. If it were possible to establish universal care home nursing metrics this would permit comparative monitoring of performance trends. Furthermore, the use of metrics would provide common bench marks to identify development priorities and measure the impact of targeted improvement interventions. This would be a challenging but justifiable endeavour in that it would explicitly profile the contribution of nursing to the care of older people within care homes.

Nursing is uniquely positioned to support older care home residents to adapt and adjust to non disease specific later life conditions and prevent and manage geriatric syndromes. Given the potential nursing contribution and high prevalence of geriatric syndromes including delirium, incontinence, cognitive impairment loss of mobility, falls, pain, sensory impairments, pressure ulcers, malnutrition, healthcare associated infections; selected conditions may provide a legitimate focus to anchor care home nursing metrics. The proposed focus on later life syndromes in contrast to specific disease entities is related to rescue and prevention, health promotion and maintenance, functional ability so as to enable older people achieve a meaningful life within a care home. Achieving optimal health and well being and a life experience of an acceptable quality to the older person is not an unreasonable goal.

Developing Capacity & Capability

Many countries are facing nursing workforce shortages and this reality must be recognised in the international care home development agenda. Locating collaborative models that pool and deploys nursing expertise and leadership (nationally or internationally) offer the most affordable routes to advancing evidence informed gerontological nursing. Communities of practice (CoPs) have been identified as key to developing sustainable collaborative capacities for evidence informed practice (2).

Communities of Practice

A recent systematic review of literature (published 1991-2005) demonstrated the potential of CoPs as an improvement framework calling for further research of effectiveness (4). A major contribution to knowledge about cultivating productive communities of practice to advance evidence informed improvements to nursing comes from a UK longitudinal programme of research (5, 6). Tolson et al completed a series of studies between 2000-2008 which sought to develop in partnership with practitioners and older people a sustainable approach to evidence informed improvements across the range of care environments, including care homes. The research involved cycles of modelling, proof of concept testing, piloting, refinement and impact evaluations of a community of practice framework for improvement. The development phase used a mixed method social participatory design combing action research with realistic evaluation. Data collection methods included group and individual interviews, analysis of online group working behaviours, compliance with evidence linked review criteria and case studies prepared in partnership with older people. Overall the development and pilot phases contributed to raising standards of care within 57 National Health Service sites (hospital wards and community sites) and 26 independent sector care homes. The resultant CoP framework comprised three critical ingredients:

1) an internet enabled communication system and infrastructure,
2) a knowledge conversion process that aligns evidence informed care guidance with an
agreed values base,
3) a facilitated transformational learning and development framework focused on changing professional behaviour leading to sustained compliance with evidence linked review criteria.

New ways of working become sustainable through individual and collective responsibilities and actions and the sharing of the CoP know how and resources with the wider practice community associated with CoP members. Achieved changes are more likely to endure as they are a product of changing the way practitioners think and act. This is accomplished by aligning change within an agreed and shared set of values. The strength of this approach is that it has been developed in partnership with practitioners and service users. It is grounded in user experience, has been piloted within Scotland and is theoretically congruent with established organisational change, social participatory and situated learning theories. An impact evaluation testing the CoP improvement model within three contrasting care environments, hospital wards, day hospitals and care homes reported verified percentage improvements of 73-86% in the review criteria at the level of the patient (direct patient care criteria) and 32-41% in facilities level criteria improvements (such as revised unit policies), figures for the care home community of practice were

82% & and 41% respectively. These improvements were observed at 6 months and are indicative of the potential of CoPs to change professional behaviour (6).

Research Opportunities

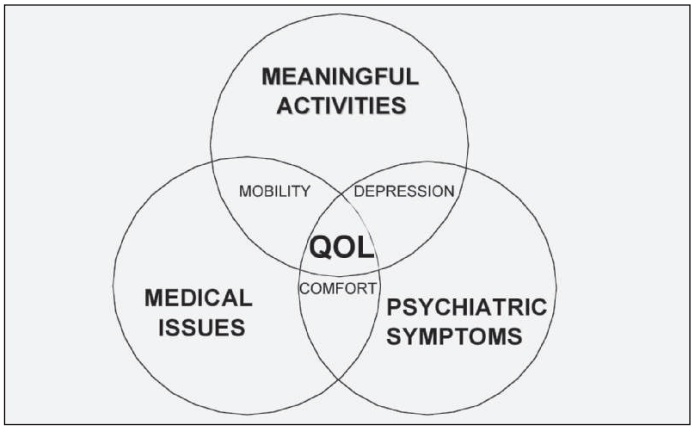
The premise of this paper is that evidence informed improvements within care home nursing need to address both clinical and care giving dimensions. A case has been made to advance the quality and effectiveness of care home nursing through research related to the management of common geriatric conditions, where the nursing contribution is central but currently reliant on a relatively weak evidence base. Suitable condition specific outcome measures will be required and it is suggested that some of these might be included within nursing sensitive metrics. In addition, mindful that evidence use is a highly contingent process vulnerable to contextually situated factors, it is essential that effective evidence implementation methods are developed for care homes and the potential of communities of practice is highlighted. 1. Booth, J., Tolson, D., Hotchkiss, R., Schofield, (2007) Using action research to construct national evidence-based nursing care guidance for gerontological nursing. Journal of Clinical Nursing. 16, 945-953; 2. Rycroft-Malone J (2008) Evidence informed prac; 3. Griffiths P, Jones S, Maben J, Murrells T (2008) Stat of the Art Metrics for Nursing: a Rapid Appraisal. National Nursing Research unit, London; 4. Li LC, Grimshaw JM et al 2009 Use of communities of practice in business and health care sectors: a systematic review. Implementation Science. 4, 27 available at http://www.implementationscience.com/content/4/1/27 tice: from individual to context. Journal of Nursing Management. 16, 4404-408; 5. Tolson D, Schofield I, Booth J, Kelly T, James L (2006). Constructing a new approach to developing evidence based practice. World Views Evidence Based Practice 3, 62-72; 6. Tolson D, Booth J, Lowndes A (2008) Achieving evidence-based nursing practice: impact of the Caledonian Model. Journal of Nursing Management 16, 682-691.

END-OF-LIFE CARE FOR PEOPLE WITH PROGRESSIVE DEMENTIAS: PROMOTING QUALITY OF LIFE, *L. Volicer (USA)*

Progressive dementias include Alzheimer's disease, vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. Although symptoms of these diseases differ in earlier stages, they are very similar once they reach an advanced stage. Advanced progressive dementia may be considered to be a terminal disease because there is no treatment that will cure it or stop its progression. Therefore, comfort and quality of life are two important goals of dementia care at this stage of the disease. Three aspects of care have to be addressed to promote quality of life. People with dementia should be provided with meaningful activities, receive appropriate medical care, and their behavioral symptoms of dementia have to be treated (Fig). Promotion of quality of life should continue to be the goal of care in advanced dementia until the end of life because progressive dementias do not result in a persistent vegetative state. Therefore, even people with advanced dementia require pain control, symptom management and attention to their psychological and spiritual needs.

Meaningful activities

Meaningful activities have to be provided because individuals with dementia have deficit of the executive function and are not able to initiate these activities themselves. For moderate dementia, group activities should involve physical exercises, simple mental exercises (e.g., word games, trivia, sorting), sing-alongs and creative activities such as simple crafts. Integrating beverages and snacks as part of meaningful activities in a social setting throughout the day improves nutrition and hydration. The activities should be provided as a continuous activity programming, available for most of the waking hours, 7 days/week. Effective program of meaningful activities results in decreased need for psychoactive medications, decreased agitation, improved nutritional status and may also result in decreased incidence of falls (1).



As dementia progresses, some individuals may not be able to participate in group activities. They may nap during the day and are unable to communicate verbally. The appropriate activity program for these individuals is Namaste Care (2). Namaste Care takes place in a room with soft music, lower lights and scent of lavender. In this peaceful environment residents with advanced dementia are gathered so they are not isolated in their rooms or placed in a hallway. A Namaste carer engages residents in activities of daily living provided as meaningful activities, e.g., washing and moisturizing residents' face, providing loving touch without gloves, and talking to the resident. The emphasis is on engaging the resident instead of on completion of the task. Residents are placed in comfortable recliners and are offered realistic dolls or stuffed cats and dogs if these items bring them comfort. Liquids are offered in small sips throughout the Namaste Care day. The program is an enhanced nursing care, should be provided 7 days/week, and does not require additional staffing.

Medical care

Medical care should carefully balance burdens and benefits of medical interventions because even simple procedures produce discomfort for an individual who does not understand

the reason for such a procedure. Aggressive procedures that may not be appropriate in individuals with advanced dementia include cardiopulmonary resuscitation, transfer to acute medical care settings, use of antibiotics in treatment of generalized infections, and tube feeding (3). Cardiopulmonary resuscitation is rarely successful and often results in injuries and extended stay in an intensive care unit that pose a great burden for individuals with advanced dementia. Even those few who are discharged from a hospital are much more functionally impaired than they were before cardiac arrest.

Acute care setting is not suitable for individuals with advanced dementia who try to remove catheters, have to be restrained, develop pressure ulcers, and are poorly nourished. It is better to treat pneumonia and other infections without transfer because treatment in residential setting, using oral or intramuscular antibiotics, is equally or more effective as treatment in a hospital and results in less functional decline. However, use of antibiotics for treatment of generalized infections should consider that antibiotics are less effective because of the recurrent nature of pneumonia and urinary tract infections. Antibiotic treatment may just prolong dying instead of leading to long-term recovery and comfort may be maintained without antibiotics by treatment with analgesics (eg., morphine), antipyretics and oxygen if necessary. Overuse of antibiotics leads to adverse effects that include development of resistance to antibiotics (e.g., MRSA) and Clostridium difficile infections.

Advanced dementia results in food refusal, choking on food and liquids and eventually inability to open mouth and swallow. These problems may be decreased by modification of diet texture, treatment with antidepressants and appetite stimulants (e.g., dronabinol), and by careful hand feeding. Tube feeding should not be used in people with advanced dementia because it does not provide any benefits. It does not prevent aspiration pneumonia and might actually increase its incidence. Tube feeding may increase patient's discomfort, may require restraints, and eliminates enjoyment of tasting food and of contact with caregivers during the hand feeding. It is important to realize that patients who are dying do not experience thirst and hunger and the only discomfort may be caused by dryness of mouth that can be eliminated by small sips or by spray of artificial saliva. There is an advantage of dying while dehydrated because dehydration decreases respiratory and gastrointestinal secretions eliminating need for suctioning and preventing vomiting and diarrhea. Dehydration also decreases the perception of pain because endorphins are released together with vasopressin.

Behavioral symptoms

Treatment of behavioral symptoms of dementia is as important as treatment of pain in individuals with cancer. It is important to distinguish symptoms that occur when an individual is solitary and those that occur when the individual interact with others. The most common behavioral symptoms that occur when the individual is solitary are agitation and apathy, while the most common symptom during interaction with others is resistiveness to care (4). Agitation may be caused by physical and environmental stimuli; e.g., pain, hunger, thirst, need for toileting, inappropriate temperature, and noise. It is important to eliminate these stimuli before considering that the symptoms are caused by dementia. Both agitation and apathy should be first managed by providing meaningful activities. However, if agitation persists, it could be due to depression or hallucinations and delusions. Antidepressant treatment is often effective and antipsychotics should be used only if the patient experiences bothersome delusions or hallucinations.

Resistiveness to care is often due to lack of understanding of caregiver's intentions when an attempt is made to provide care. The patient resists unwanted attention and if the caregiver insists on providing care, the patient may strike out to defend him/herself. Such an individual is sometimes considered to be aggressive or abusive, but the patient actually considers the caregiver to be an aggressor. The second most important factor causing resistiveness to care is depression. Depression may actually result in a behavior that is considered abusive by the caregivers even in absence of resistiveness to care (5).

Resistiveness to care may be decreased or eliminated by improving communication between the patient and the caregiver. The patient may not understand spoken explanation because of aphasia but may understand the caregiver's intentions if he/she is brought to familiar environment suggesting the activity, e.g., barber shop or home-like bathroom. Resistiveness to care may be also avoided by delaying the care or by distracting the patient by reminiscence during care. Resistiveness to care is most common during bathing but it may be eliminated by substituting bed (towel) bath for shower or tub bath. Bed bath is equally effective in cleaning and eliminating microbial counts on the skin and is much better accepted by the patients.

If improved communication is not sufficient to eliminate resistiveness to care or if abusive behavior occurs outside of the care situation, antidepressants should be the first medication to use. Antipsychotics should be used as the first line therapy only if the resistiveness to care or abusive behavior is clearly caused by delusions or hallucinations. Antipsychotics have many adverse effects including increased incidence of sudden death and increased mortality rate. In some cases, however, antidepressant treatment may not be completely effective and requires addition of an antipsychotic to enhance its effectiveness.

Advanced dementia inevitably diminishes quality of life. However, by addressing the three important aspects of dementia care listed above, it is possible to promote quality of life until the end of life. 1. Volicer L, Simard J, Pupa JH et al. Effects of continuous activity programming on behavioral symptoms of dementia. Journal of the American Medical Directors Association 2006;7:426-431; 2. Simard J. The End-of-Life Namaste Care Program for People with Dementia. Baltimore, London, Winnipeg, Sydney: Health Professions Press, 2007; 3. Volicer L. End-of-life care for people with dementia in

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