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# THE FACTOR OF AGEING IN INTERNATIONAL DEVELOPMENT CO-OPERATION\*

FREDERICK F. FENECH

Ageing, as an issue of world concern, was for the first time brought to the notice of the world community in 1969 by a 'note verbal' of the Government of Malta to the Secretary General of the United Nations when it requested the question of the Elderly and the Aged be included as a supplementary item of the agenda of the 24th Session of the General Assembly. The UN Assembly at the 24th Session adopted a resolution giving priority consideration to the question of the World's Ageing Population. Up to that time, issues related to the elderly and aged had not attracted much attention at the international level. The discussions, which followed in subsequent years, led to the holding in 1982 of the UN First World Assembly of Ageing in Vienna; the Vienna International Plan of Action on Ageing focused on the specific needs of older persons and the socio-economic implications of ageing in developed countries. One of the outcomes of the Vienna Plan was the recognition of the need to have more trained personnel to look after the elderly. In 1987 the UN Economic and Social Council in its resolution 1987/41 recommended to the Secretary General the establishment of the International Institute on Ageing - opened in Malta in 1988 following agreement between the UN and the Malta Government. The focus of the Second UN World Assembly in 2002 in Madrid shifted considerably; it promoted the view of ageing from the perspective of both developing and developed countries. This intergenerational policy approach pays attention to all age groups with the objective of creating a society for all ages and a shift from

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developing policies for older persons towards the inclusion of older persons in the policy-making process. In between the two world assemblies, the UN principles for older persons were adopted in 1991.

In this presentation I will discuss the various demographic issues which are having an impact on ageing as well as how they relate to both the developed and the developing countries. I will also deal with the various initiatives, both national and international, which are being taken to implement the Madrid International Plan of Action. Such implementation has to be carried out by the Governments which have signed up to the Madrid Declaration with the support of UN Agencies, International and National organizations and civil society.

## Demographic Issues

The change in fertility and mortality rate in the 20th century produced a revolution in longevity resulting in a world which will rapidly age during the 21st century. Indeed the 21st century has already been termed "The Age of Ageing". The increasing longevity is evident in both developed and developing countries except in Sub-Saharan Africa when prolonged economic hardship made worse by HIV/AIDS pandemic has reversed the life expectancy gains.

It is estimated that globally, every month, 1 million people turn 60 years of age. The number of older persons is projected to increase to 2000 million in 2050 from 600 million in the year 2000. (Table 1) The increase will be greatest in developing countries



and their numbers are expected to more than double reaching 850 million by 2025 - 75% of the world's older persons. (Fig 1) The age structure of the population will change through an increase in proportion of older people and a declining proportion of children. The proportion of older people will be rising from 8% to 19% by the year 2020 whilst that of children will fall from 33% to 22 %. In the developed world the very old (age 80+) is the fastest growing group. Women outlive men in virtually all societies; in very old age, the ratio of women / men is 2: 1.

Indeed by 2050, for the first time in history, the number of older persons in the world will exceed the number of young. In the developed world and in some countries with economics in transition, the number of older persons already exceed the number of children.

Accompanying the progressive ageing of the population is the emergence of the so called fourth generation (those over 80 years). The fastest growing group of the older population are those age 80 years and over - "the oldest old". In the year 2000 they numbered 70 million (11% of those over 60 years); these numbers are projected to increase more than 5 times by 2050 to make up 19% of those over 60 years. (Fig. 2) By the same year, the number of centenarians is expected to increase 18 times.

The demographic transition, which until recently was mostly viewed as a phenomenon of developed countries, has started to become a feature of many developing countries. Although most developing countries still have relatively young populations, many are projected to experience, during the coming 3 decades, remarkable increases in the numbers and proportions of older persons. Indeed China with 1/5 of the world population, represents an example of the problems countries experiencing rapid demographic transition will be facing in the coming decades, though China has specific problems of its own. Between 2000 and 2050 there will be a marked reduction of younger persons and the marked increase in the older age groups. A recent study estimates China's population will peak to 1.4 billion in 2050 from 1.3 billion in 2003. The result of this will be rapid ageing of the population.

Since the mid-nineties, INIA, following agreement with a number of Chinese organizations such as CNCA (China National Committee on Ageing), BCAB (Beijing Civil Affairs Bureau), and others has been holding regularly training programmes in the various fields of ageing. These programmes are held both in China and Malta.

China has 130 million elderly citizens who make up just over 10% of the population; this figure is predicted to rise to 31% in 2050. There is also a very rapid increase of the oldest old; with ageing being much more prominent in the rural areas. This means that the working population will have to provide for an increasing number of those who have retired, thus putting pressure on young people as traditionally the family used to look after their elders. It is suggested that by 2025, parents will have few offspring on whom to depend. A growing number of single young people are finding themselves faced with the daunting prospect of caring for parents and 4 grand parents - a phenomenon known as the 4 - 2 - 1 family. (Table 2) Moreover many Chinese parents have only 1 child and prefer it to be a boy; this will lead to a gender imbalance. The outcome will be fewer brides and therefore fewer children.

In developed countries, population ageing was a gradual process spread over a long number of years. In France it took 82 years and in Sweden 114 years for the population aged 65 years and over to double from 7% to 14%. In a number of developing countries, these changes are taking place in a much shorter time frame. (Table 3) China and India, the world's most populated countries which account for about 50% of the world's older persons, are projected to make this transition in a time span of 25 - 28 years.

This poses a major resource challenge to countries facing the simultaneous challenge of ageing and development. Dr. Gro. Harin Bruntland, the former Director General of WHO, very aptly commented on the changes in time frames of ageing between developed and developing countries and I quote: "We must be fully aware that whilst developed countries become rich before they become old, developing countries will become old before they become rich".

In developing countries, population ageing is projected to be more rapid in the first half of the 21st century. Although in absolute numbers, the developing regions account for the majority of the world's older persons, the developed countries are still definitely older when one considers the relative weight of the older population. The decline in fertility level, reinforced by the continued decline in mortality level, is producing fundamental changes in the age structure of the population of most societies, most notably record increase in the proportion of older persons, including a growing number of very elderly persons. Indeed as birth rates are now very low and there is not much room for further decline, decreased mortality amongst the oldest old is taking over as the primary factor for population ageing. The advances in medical technology are contributing to this decline.

However it has to be said that the vast majority of older people remain physically fit into later life. They grow older in good condition of health, autonomy and productivity. A minority of elderly with chronic diseases as well as the growing number of persons who reach a very advanced age pose a heightened demand for health and supportive services. This is occurring at a time when they have less supportive relatives.

The overwhelming proportion of older persons in developed countries live in urban areas, whilst those in developing countries live in rural areas. The next two decades are likely to produce a further shift of the rural population to the urban areas as a result of increasing industrialization. In 1994, 45% of the global population lived in urban areas and this is expected to rise to 56% by 2015. The most rapid rates of urbanization will occur in developing countries, rising from 26% in 1975 to a projected 50% by 2015. The outcome of such changes is that the assistance to the elderly from the traditional support systems are being placed under considerable strain. In many developing countries there is no social security net on which to rely in old age with the result that in such countries increasing longevity meant that people lived longer in poverty. It is in these developing countries, that have high poverty risks, where there will be the

fastest growth of the older population in the next 15 years - it will increase by 48% in sub-Saharan Africa compared to 30% in OECD countries. With the time span set up by the Millennium Development Goals (MDG) developing countries will see their older population increase by more than half. Some of the countries have made considerable progress, but others are unlikely to achieve the MDGs by 2015. Rapid ageing with poverty is a development concern. Older persons in sub-Saharan Africa are at risk because the demographic structure is changing in a unique way with HIV / AIDS killing prime age adults putting in jeopardy the traditional safety net of family support. Broad based policy measures need to be developed to cope better with the demands placed upon them.

Historically, women have not always lived longer than men. Economic development and social change removed some of the major risks to women's health. The preponderance of women becomes more pronounced with advancing age, reaching its highest amongst those over the age of 80. (Fig. 3)

Indeed the problems faced by these women comprise a substantial share of the problem of older persons. Women in the 75 + age group are often widowed and lack financial resources. While the vast majority of older women in developed countries cope with adjustments to widowhood, in developing countries older women are almost always dependent on their families. Widowhood remains one of the leading factors associated with poverty, loneliness and isolation. The MIPAA noted the particular vulnerability of older women to disability owing to gender differences in life expectancy and disease susceptibility as well as gender inequalities over the life course.

International action plans developed at UN conferences encourage countries to review their legal frame-works for eliminating discrimination between men and women. NGO's and women's organizations in both developed and developing countries, are giving more attention to the urgent issues faced by older women. There are some encouraging examples of older women themselves forming advocacy groups and projects that lead to empowerment and a better quality of life.



## Social Policies and the Madrid International Plan of Action

Though demographic data are essential for policies and action programmes in the field of ageing, the implications of population ageing have social, health, economic and political significance on society and on the institutions and services. The ageing of population poses unique challenges and

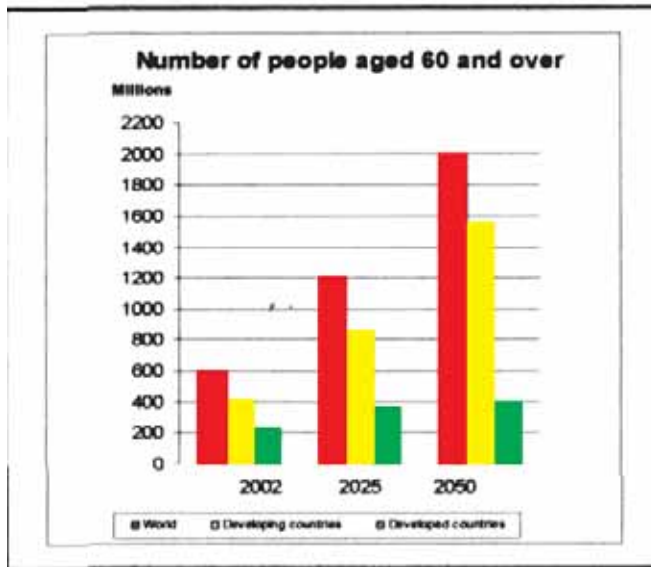


Fig. 1

the attention of every government is aimed at the very issues that arise from this process. These unprecedented demographic changes are taking place at the same time as other enormous changes are occurring. Among these are the Information

Facts about Ageing	
•	In 2000 there were 600 million people aged 60 and over (10% of the world population); there will be 1.2 billion by 2025 and 2 billion by 2050 (21% of the world population).
•	Today, about two thirds of all older people (375 million) are living in the developing world; by 2025, it will be 75% (850 million) and 79% (1.5 billion) by 2050. The number of older persons in developed countries in year 2000 were 232 million and projected to increase to 394 million in 2050.
•	In the developed world, the very old (age 80+) is the fastest growing population group.
•	Women outlive men in virtually all societies; consequently in very old age, the ration of women/men is 2:1.

Table 1

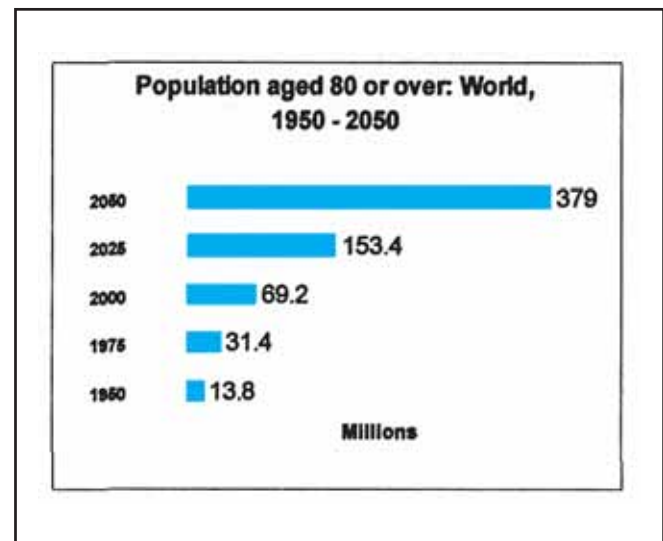


Fig. 2

Technology Revolution, Globalization of trade and finance, and the ever increasing technological development. The next generation of elderly persons

### CHINA

#### Demographic issues:

Population 2003 – 130 million elderly (10% of population)  
2050 – 434 million elderly (31% of population)

Rapid increase of the oldest old

Working population will have to provide for an increasing number of those who have retired.

The 4 - 2 - 1 family phenomenon.,

Table 2

will have to deal with the changes brought on by the technological revolution. The challenges created by this ageing population includes employment, healthcare, discrimination and access to services. This requires governments to think much more widely about how to meet the needs of older people. At the core of this is the need to change fundamentally the way one thinks about ageing. It is increasingly not about dependency but about breaking the link between age and dependency by encouraging and supporting older people to play an even greater role in society. Indeed countries all over the world show a slower growth of the labour force. In developed countries, the declining labour force would require the increased participation of older persons. To meet these challenges, the issue of

**Rapid Increase of Ageing in the Developing World**

Year 2000 – 7 % of Population > 65 years  
 Year 2025 – 14% of Population > 65 years

This increase took 120 years in the Developed World.

Table 3

ageing should not be treated in isolation but should form an integral part of an overall national development programme which takes into consideration the cultures and traditions of each country. Each country has to find the mix of policies that will work for them.

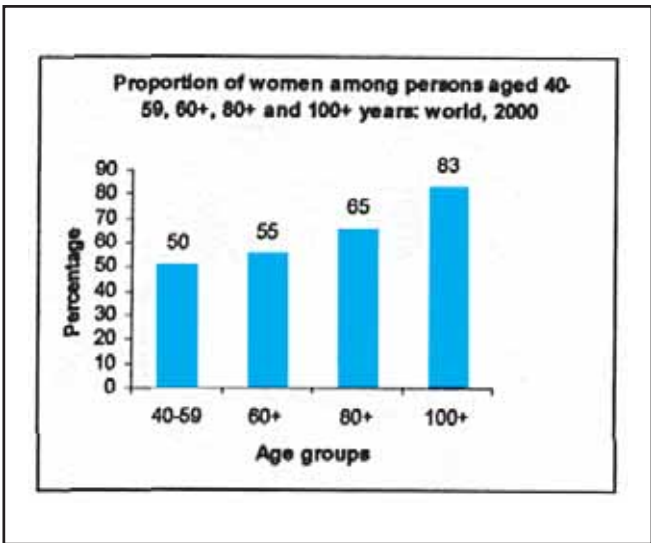


Fig. 3

In 2002, during the 2nd World Assembly on Ageing organized by the UN in Madrid, the International

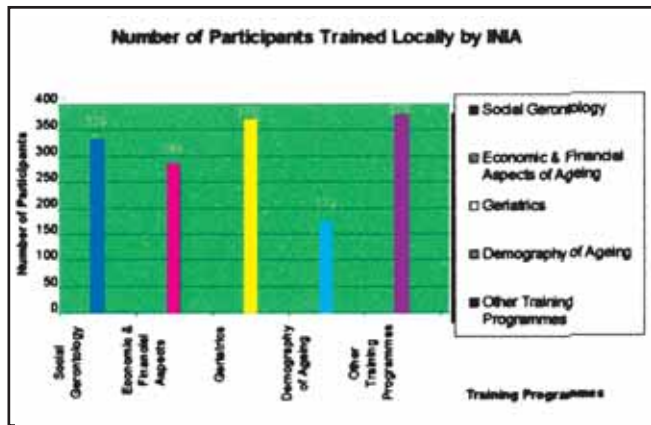


Fig. 5

Community reaffirmed its commitment to work towards the establishment of a society of all ages. To meet these challenges MIPAA committed Governments to include older people in policies to achieve the MDG. Many commitments in the MIPAA reinforce the role of older persons in society such as their participation in development efforts, empowerment of older persons, gender equality and eradication of poverty, full enjoyment of human rights, provision and access to health care and social protection. The Madrid Plan emphasises that implementation would require sustained actions to respond to the demographic changes. Developing countries will not be able to meet the challenges needed to implement the Madrid Plan of Action without substantial support from developed countries. An important measure to facilitate the implementation of the Madrid Plan is by mainstreaming the concerns and issues relating to older persons to the centre of attention and into a wider policy agenda. To generate attention concerning mainstreaming, the theme chosen for the International Day of the Older persons in 2003 was

AMERICAS		EUROPE		AFRICA		ASIA	
Barbados	50	Macedonia	55	Egypt	106	China	368
Brazil	27	Russia	24	Ghana	32	India	123
Mexico	30	Belarus	33	Kuwait	57	Philippines	20
Panama	70			South Africa	55	Singapore	91
				Tunisia	115	Thailand	20

Fig. 4

Mainstreaming Ageing: forging links between Madrid Plan and the Millennium Development Goals. Various UN programmed specialized agencies as well as NGOs have made efforts to mainstream the concerns of older persons in their respective agencies. UNFPA stress to mainstream ageing into its areas of work – reproductive health, gender issues and humanitarian responses, WHO focuses on principles and methods of developing health care systems that are responsive to ageing, DESA organizes expert group meetings on modalities for review and appraisal and on national implementation of MIPAA, HelpAge International focuses on HIV/AIDS and older persons as caregivers whilst the International Institute on Ageing has focused on education and training of personnel from developing countries in the various fields of Ageing.

### **International Institute on Ageing**

The paramount need for training and education in the various fields of ageing was first emphasized in the Vienna International Plan of Action in 1982 where it laid particular stress on the need of training all those who are actually working or intend to work in the field of ageing. Twenty years later, the Madrid Plan constantly reiterated in various articles, the importance of training and of having trained personnel. Issue 4 in the Second Priority Directive is totally devoted to training of care providers and health professionals. This is indeed the UN mandate of the International Institute on Ageing in Malta. The objective of the Institute has been and still is to undertake training programmes to fulfill the training needs of developing countries and to act as a practical bridge between and among developed and developing countries. The objectives of training have been, and remain, to enable people to evolve appropriate policies in various field of ageing. We believe in the importance of training trainers in order to achieve the multiplier effect when the need for trained personnel is so great.

Since 1991, the Institute, in partnership with UNFPA, has trained 2,870 participants from 128 different countries both in Malta and overseas. This is done in two principal ways: by short and longer training programmes in Malta and short programmes

overseas. The in-situ training programmes started in 1995. We organize 4 - 5 such programmes a year in such diverse countries as China, India, Thailand, Singapore, South Africa, Ghana, Tunisia, Egypt, Mexico. Such programmes were held in 17 different countries. In January of this year, we held one in Belarus and this month we will be having another one in St. Petersburg. These in-situ courses are held in collaboration with Ministries, Universities and NGOs. (Fig. 4) They concentrate on the situation in a particular country or region and contribute to local capacity building.

Since 2003, the Institute has increased its capacity building potential by establishing satellite centres in various parts of the world. The first such centre was established with SAGE (Singapore Action Group for Elders) for the Asian countries, the second with CASP (Community Aid & sponsorship Programme) in India for the SARC countries. It is planned to establish such centres in other regions.

The short programmes are planned by international experts with experience of developing countries. They are held each year in Malta and attract participants from all over the developing world. (Fig. 5)

The short programmes cover the following topics:

- Social Gerontology
- Economic and Financial Aspects of Ageing
- Geriatrics
- Demographic Aspects of Population Ageing and its implications for socio-economic development, policies and plans

These are tutored by some of the world's leading experts in the field as well as local faculty.

The long term course sponsored by INIA is a 9 month diploma course in Gerontology and Geriatrics conducted by the European Centre of Gerontology and Geriatrics at the University of Malta. So far INIA has sponsored and given fellowships to 88 participants from developing countries with the support of UNFPA, the Merck Institute of Ageing and Health (USA) and other institutions.

INIA's impact on creating awareness and training in developing countries has been substantial. The growing awareness that is emerging is resulting in very rapid increase in demand for participation in our courses, both for those held in Malta and the in-situ and regional courses. In addition we remain in contact with those who have participated in our courses.

In all of our programmes the recommendations, set out in the MIPAA are highlighted. Emphasis is placed on active ageing, supported by a policy of participation of older people and their integration in society. Through intergeneration solidarity, they contribute to the creation of a Society of all Ages. In order to prepare society to face the challenges of population ageing, one needs to have a national strategy to ensure that goals of active ageing are achieved. Problems faced by countries include lack of funds, insufficient training of personnel for implementation of the policies and shortage of staff. Poverty reduction is a priority for many countries in the developing regions of the world and debt relief especially in Africa is a necessary measure. Good health is a prime factor to ensure good quality of life. Although population ageing may not result in an increasing proportion of elderly persons in poor health, the number is almost certain to increase resulting in increased social and economic demands on individuals, families, communities and nations with substantial impact on formal and informal social care and financing of medical services in general. The provision of basic health services is therefore vital.

To meet the challenges of population Ageing:

1. Ageing should form an integral part of an overall national development programme for each country with active participation of the elderly. Countries should be supported and helped in setting national targets for elderly.
2. Research into the impact of population ageing and economy. Age de-segregated data on socio-economic situations of older people should be obtained and analysed.
3. Increase training opportunities and establish a programme of education and life-long training.

Awareness raising of MIPAA and what it contains should feature in the activities of NGOs.

4. Evaluation of current laws; if necessary formulate new laws by reflecting the concerns of older people; the laws should also make up for the disadvantages encountered by older people by tackling discrimination.
5. Governments, NGOs, international organizations and donors should work and mainstream together in order to create a better coordinating mechanism on policies and practices. There should be more systematic sharing of best practices.
6. Every country should have a National Committee on Ageing, whose remit would be to protect the interests of older persons.
7. The elderly should have the ability to continue working with income generating work and thus contribute to the economical progress of their country.
8. Promoting healthy life-style in old age.
9. The crucial role that older people play in their families and in their communities recognized and supported.
10. Measures in support of income security, social protection and poverty reduction and prevention.

In conclusion, clearly the challenge is great. The foremost challenge lies in supporting the new opportunities for older persons and the benefits for society that arise from the ageing of populations. Policy-makers gazing into crystal-balls may well raise the spectre of a crippling burden in health and welfare costs, fearing that a diminishing pool of carers and the growing dependence of more old people will lead to intergenerational stress and ageism. Ageism is sadly still with us. Older people are often stereotyped as passive and helpless when in actual fact, the majority of older people living in the developed and developing world are healthier.



The elderly must be considered as a valuable resource - they have a wealth of knowledge and experience that can be utilised for the benefit of

Society as a whole. We must all endeavour to see that this valuable resource is not wasted. **Ageing is an opportunity and not a threat.**

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**Professor FREDERICK F. FENECH M.D., FRCP.**  
**Director, INTERNATIONAL INSTITUTE ON AGEING**  
**(UNITED NATIONS - MALTA)**

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## **MERCK INSTITUTE FELLOWSHIPS**



The International Institute on Ageing, United Nations – Malta has received a grant from the Merck Institute of Ageing and Health, Washington D. C. for the years 2003, 2004 and 2005 for Training Programmes, which are held in Malta. These funds support the educational activities of 8 Fellows from developing countries participating in the Short Training Programmes in Social Gerontology, Economic and Financial Aspects of Ageing, Geriatrics and Demographic Aspects of Ageing as well as 2 participants in the 9-month Postgraduate Diploma Course in Gerontology and Geriatrics at the European Centre for Gerontology, University of Malta.

Applications for the above Fellowships will be received by Professor Frederick F. Fenech, Director of the International Institute on Ageing, United Nations – Malta, 117, St. Paul Street, Valletta VLT 07, Malta, e-mail **ffn@inia.org.mt**.

The closing date of applications can be obtained from the Institute's website, **www.inia.org.mt**.

# ELDER ABUSE WITHIN THE FAMILY

JORDAN I. KOSBERG  
BARBRA L. TORGUSEN

## ELDER ABUSE WITHIN THE FAMILY

Elder abuse exists in every country of the world. The International Network for the Prevention of Elder Abuse, a NGO affiliated with the U.N., has members from many countries representing all continents. As the problem has been found to occur mainly within a family setting, there is a need to understand better the family dynamics that are associated with the abuse of older relatives. It is believed that those who study elder abuse have used traditional definitions of elder abuse that have changed very little over the years, yet changes in the family require a reconsideration of the causes of elder abuse. An understanding of changes in the traditional family should result in more effective preventive efforts of the problem.

Current and emerging forces related to abuse of the elderly within the Family need to be considered and anticipated both in developed countries, where elder abuse has long been identified as a problem, as well as developing countries, where elder abuse is of a more recent concern. This article identifies the causes and consequences of elder abuse in countries where families are undergoing changes over time.

### Meaning of "Family"

Research on elder abuse has consistently found that this is perpetrated primarily by members of the family (Schiamberg & Gans, 2000). Thus, it is believed necessary to focus upon the family to understand better the dynamics between family members. The definition of "family" has undergone considerable change. Often, the family includes an extended arrangement of relatives (grandparents, parents, brothers and sisters, aunts and uncles, and cousins) that serves as mutual support systems and

an economic resource. This was seen in the past in developed nations and still exists in some rural or less-developed regions. Following industrialisation and urbanisation, the family in developed nations started being referred to as "nuclear" and seen to include mainly parents and young children. Believing that the older family members have been excluded from the nuclear family is not always correct, as older relatives often provide assistance to the family (such as child care, financial support). As a result of societal changes leading to the desire of older persons not to be dependent upon their family, they turn to their family only when independent living is no longer possible. Currently, in many developed nations, the interaction between family members is described as "intimacy at a distance," whereby older relatives live apart from their adult children but either within commuting distance or with on-going contact with their children by telephone, visits, and e-mail.

Those who are considered family members have changed over time. It is not unusual to use the term "informal support system" in a more comprehensive manner to include family members and friends. In the absence of family, friends and neighbours can provide valuable assistance and companionship. In some families, friends and neighbours can be counted on to provide adequate and reliable care, more so than relatives. Within certain cultures, the role of non-family members is similar to that of relatives by birth or marriage. For many persons with Spanish backgrounds, to be named a *Compadresco* (Godparent) for a child is an honour, but one coming with certain responsibilities. So, too, in the United States, many African Americans are referred to as "fictive kin," and while not relatives in the traditional manner, provide assistance that can be even more important than that provided by relatives.



Currently, in many societies, the family is undergoing redefinition. Whereas in the past the family was considered composed of a father and mother and their children, in many countries the family consists of one parent raising a child or children, married or unmarried heterosexual couples, and gay and lesbian couples with or without children. Some individuals believe themselves to be a part of a family, whereas others might consider these individuals to be a part of a clan or cult that shares common religious or spiritual beliefs or lifestyles.; the point being that those who study elder abuse within a family setting must be cognizant of variations in the definition of the family over time and in different cultures and countries.

This article seeks to address changing definitions of the family as related to the existence of elder abuse, and the following section describes how elder abuse has been linked to the family. As will be noted, there are various definitions of elder abuse.

**Definitions of Abuse.** There have been different definitions of elder abuse that can include physical abuse (such as hitting, pushing, shaking), psychological abuse (including emotional neglect, verbal assaults, and isolation), theft and financial misappropriation (including fraud, theft of money or property) and denial of rights (including self-determination and choices in friends, living arrangements, and social relationships). The U.S. National Elder Abuse Incidence Study's Final Report (1998) provides the following definitions of elder abuse: physical abuse, sexual abuse, emotional or psychological, neglect or abandonment, financial or material exploitation, and self-neglect. Potentially, elder abuse involves either acts of commission or omission. In an effort to simplify some of the causal theories on elder abuse, Kosberg (1988) dichotomized the reasons for elder abuse that are perpetrated by family members. The first explanation suggests that there are some family members who are inappropriate to caring for dependent relatives of any age; such family members include those who are substance abusers, cognitively impaired, physically or mentally ill, unmotivated, or unemployed or otherwise impoverished. The second general explanation for family abuse of

elderly relatives directs attention to caregiving burden (or burnout) that leads to ineffective care. Indeed, the movement for "care to the caregivers" reflects a widespread belief that by giving attention to the needs of family caregivers of older persons, there is an increase in the quality of care given to the older care recipient (Nahmiash & Reis, 2000).

**Cross-National Findings.** Kosberg, Lowenstein, Garcia, and Biggs (2001) have discussed differences in the definition of elder abuse both between and within different countries. The study of elder abuse in different countries has been influenced by those in developed nations (such as the U.S., Canada, Great Britain). Kosberg and Garcia (1995) edited a book that presented elder abuse information authored by individuals from 10 countries: India, Poland, Ireland, Finland, Australia, Norway, Hong Kong, Greece, South Africa, and Israel. While there were significant variations in the definition of elder abuse in these countries, generally there was involvement of family members. For example, Norway includes family disharmony, Hong Kong includes "elder dumping" of elderly relatives, and India includes disrespect by a daughter-in-law.

It has been found that the high suicide rate among older persons in some countries may result from the perceived abusive nature of institutions for older persons in countries where traditionally old people have been treated with filial piety (reverence) by their families (Smith, 1999; Sung, 1990). In Sweden, family caregiving responsibility has been emphasized as an economically attractive alternative to traditional public provision of care by the government; yet, can be viewed as abusive by both older persons and their family members (Johansson, 1997).

**Variations within Countries.** The differences in values of the population between countries may well approximate the cultural variations within many nations. In U.S., Annetzberger, Korbin, and Tomita (1996) found variations in the definition of elder abuse between Japanese-Americans, Mexican-Americans, Korean-Americans, and African-Americans. Indeed, such diversity exists in virtually all countries (Kosberg, et al. 2002). For example, in

the London Borough of Harringay (with about 500,000 people), one might encounter individuals representing 26 different language groups. In Israel, there are a vast number of different groups representing different religions and great variations within each religion, and there is great variation of ethnic backgrounds within and between Israeli Jews and Israeli Arabs. All this is to suggest that the definition of what is considered elder abuse must reflect similar variations as the groups that compose a country.

## A FAMILY PERSPECTIVE

A family systems view of elder abuse is appropriate to explain current and future abuse of older members of the family. Such a view involves the relationship of societal influences on the family and its members, and the relationship between characteristics of family members and the treatment of older relatives. Such influences will be discussed in the following sections.

### External Influences on the Family

Members of the family, and the family itself, are affected by the characteristics of the community and nation, and the economic prosperity of a country is seen to be related to the quality of family life. Important also are dominant societal values regarding gender, family caregiving, and the value of older persons. Finally, the family is affected by religion and politics, health conditions, and the family's geographic location.

**The Economy.** The economic status of a nation has a direct impact upon its citizens. In times of economic depression, the less fortunate are further disadvantaged and must compete for limited resources. Such economic problems are related to unemployment, underemployment! and the stress evoked by these difficulties. There is a relationship between economic problems and the likelihood of child and spouse abuse, intra-family violence, inter-group conflict, and various forms of crime and victimization. It seems apparent that the amount of funding allocated by a nation to provide resources assisting the elderly to maintain their independence,

or for supportive services for family caregivers, will be proportional to caregiving burden and the possibility of elder abuse. Improved economic conditions will probably result in the reduction of such adversities, although research is needed to prove such an assumption.

As previously discussed, the economic conditions in a nation are related to those of the family that, in turn, are related to the existence of abuse and maltreatment of the elderly. Thus, there is need to monitor economic fluctuations within a country and see it as a measure of family solvency and the possibility of abuse of its most vulnerable members. Family caregivers who are forced into the caregiving role, as they cannot afford alternatives, may feel angry and turn their feelings towards the source of their frustration: the older person. It is believed that older persons who have families that can afford transportation, medical care, and receive outside assistance are less likely to experience the stresses that a family without financial stability would experience. So, too, might impoverished economic conditions result in adult children becoming dependent upon older parents. Abuse can result from the economically-dependent child's anger, embarrassment, or the unrealized expectations of assistance from the parent.

**Societal Values.** Each society holds predominant values. In some countries, such values can include independence, achievements, and youthfulness; in other countries there is a premium on conformity, harmony, and cohesiveness. Obviously, the value of care to be given to older persons will also vary. As a result of immigration or emigration, and/or passage of time, values change from generation to generation. A culture gap exists when older generations have traditional expectations regarding family caregiving and younger generations hold different values that embrace greater freedom from family responsibilities. A clash in values may be related to the possibility of abuse and maltreatment of older persons. On one hand, older people may believe they are being abused when their families fail to uphold expectations for care and support. On the other hand, family members may believe they are being coerced (trapped) by traditional cultural



expectations to which they must sacrifice their freedom by having to care for elderly relatives. The caregiving behaviours of these “trapped” family members need to be of concern.

**Gender Norms.** Cultures also define the normative roles for males and females (Kosberg & Garcia, 2004). Societal conflict between them can result from differing views of gender appropriate behaviour in a marriage, in the family, and in society. Discrepancies in perceptions regarding male and female roles, rights, and responsibilities can result in marital abuse, family disharmony between generations, and charges of sexism in the workplace, among others. In many countries, females are less likely to be dependent upon males (such as husbands, fathers, bosses), and less likely to suffer their abuse and maltreatment in silence. Men have been socialized to be stoic and independent, and will often suffer abuse in silence. The freedom of women to pursue education, careers, and professions, outside the home, is a hallmark of the past century. Yet, discrepancies still exist between women's desires for independence and freedom and some men's attempted efforts to maintain traditional gender role distinctions. This can be seen in some traditional families where males vigorously seek to enforce their dominance over female members of the family. Abuse can result.

**Health-Related Issues.** Improved medical technology exists in an increasing number of countries, and more people are reaching their later years. Paradoxically the growing number and proportion of the elderly lead to the possibility of increased elder abuse. Generally speaking, the older the age cohort, the more likely they will need assistance with activities of daily living (such as cooking, bathing, shopping) and the greater the possibility of caregiving burdens. The AIDS epidemic has resulted in the deaths of countless parents of children who will be raised and cared for by their grandparents. Thus, there is a relationship between the number of elderly persons and the possibilities of abused older persons.

The physical, mental, and cognitive condition of family members has been found to be related to the

existence of elder abuse. With population aging comes an increased probability that family caregivers (such as a spouse or adult child) will themselves be old and physically and cognitively impaired. So, too, as a result of medical advancements, might an impaired and dependent adult child (one that may be mentally retarded or mentally ill) become the caregiver for the aging parent or parents. In such cases, the ability to provide needed care in an effective and humane way may be difficult or impossible, and the possibility of abusive treatment is a valid concern.

**Migration Patterns.** There is much in-country and cross-national mobility in the world, as people move away from adversities (such as tribal conflict, political disruptions, poverty, famine, droughts) and/or toward greater opportunities (such as jobs, housing, education). The result of such mobility is complex and potentially disadvantageous for older people. Younger persons generally move from rural to urban areas, as well as relocate to other countries, and the elderly members of the family are often left behind. Elderly persons moving to urban areas, possibly to follow children or to be closer to needed community resources, may be especially vulnerable in an urban area due to traffic, crime, and lack of familiarity with the new setting. Older people who relocate from one country to another, mainly to be closer to children, leave behind their native land and are often exposed to different languages, cultures, and ways of life. In this new and different country, older relatives may be especially dependent and, as such, vulnerable to abuse.

**Geographic Inequities.** For the most part, the literature on elder abuse has involved studies or case reports from urban areas. Explorations within rural areas are less frequently undertaken, and perhaps more difficult to accomplish. Some gerontologists (Cupitt, 1997) have identified the tranquil and supportive rural environment for older persons to be a myth, as rural life may involve such depressive conditions as widespread unemployment, poverty, and isolation. Additionally, rural areas often lack the range of community resources for older persons and their families as found in urban areas. More research is needed into the existence of elder abuse

in rural areas and the possibility that it may be undetected and unreported.

**Religious and Political Influences.** In Asian countries there exists ancestor worship and other religious philosophies that support filial piety. The Judeo-Christian mandate for honouring one's father and mother exists in many other countries. Yet, it is wrong to believe that a person's religion and religiosity will preclude the possibility of abuse against a family member. There is too much conflict between and within countries of the world, and within families, to believe this. The norms governing respect of, and respectful treatment for older persons are challenged by more contemporary norms regarding the importance of self and one's nuclear family. In his book, *Aging in Developing Countries*, Tout (1989) concludes his analysis of different countries by stating that not even religion could be relied upon to "stay the processes of disintegration" of marriage and the family caused by contemporary forces. While governments cannot legislate for parental respect, they can possibly provide both opportunities for roles and status, in addition to financial assistance, to older persons. For example, Communist China had roles for the elderly in neighborhoods (called "granny patrols"). Without necessary encouragement, governments will not provide opportunities to older persons and resources to their family members.

**Responsibility for the Elderly.** Around the world, countries vary in the perception of responsibility for the care of the elderly which is, in part, influenced by the existence or absence of public and private policies and programmes. In some countries the emphasis is on individual responsibility; other countries focus on the family, neighborhood, village, tribe, or parish, religious community, non-government organizations, or state, province, territory, or national government. It is believed that when the major institution that is entrusted to provide care to older persons (i.e., the family) is not willing or able to meet its perceived responsibility, the result might be abusive behaviour.

## Internal Influences on the Family

As mentioned, elder abuse can also result from individual family characteristics. There are several issues to be considered at this level to include the quality of a marriage, characteristics of family members, custodial grandparents, and threats against pets.

**Abuse in a Marriage.** There has been little attention to the relationship between the quality of a marriage and the possibility of elder abuse. Research has generally failed to differentiate between spouse abuse and elder abuse (or abuse in any permanent long-term relationship). It is believed that spousal abuse should be defined as adversity occurring throughout a marriage that continues into old age. On the other hand, elder abuse between a couple is believed to occur, for the first time, after they have entered their old age (and can result from physical or mental impairments of either the husband or wife).

It is suspected that pre-caregiving marital satisfaction is related to post-caregiving marital satisfaction and that when a marriage is not good, the caregiver may feel angry and frustrated. Wallsten (2000) found that wives are more likely than husbands to become dissatisfied with a marriage when caring for an impaired spouse. It is believed that, unchecked, marital dissatisfaction evolving into anger could result in abuse and maltreatment.

## The Consequences of Caregiving

Caregiving in virtually all countries is seen to be a female responsibility. Employed females are not excused from family caregiving for an impaired husband or parent. Yet, many females wish to continue in their jobs or careers and may not desire either to reduce their work hours or to withdraw from outside employment to care for an older relative. These competing responsibilities of work and family may be particularly problematic for females, who are called upon to provide care for aging parents during the same years in which they may already be juggling family and work responsibilities. They may become angry at facing this remnant of (what they



believe to be) out-dated and unfair gender expectations.

Older husbands may become caregivers of an impaired wife, child, or parent when there may not be any others to undertake such a responsibility. Research on the quality of care given by inexperienced male caregivers seems necessary, as good intentions will not replace competence in the caregiving role. Additionally, it has been found that older caregiving husbands are more likely to endure their caregiving burden in silence and for longer periods than wives. More information on the adverse consequences on wives being cared for by males is necessary.

***The Instability of Marriage.*** Rates of divorce and separation in the world are increasing. In some countries, divorce -- along with widowhood -- has resulted in increasing rates of remarriage. These somewhat contemporary dynamics of increased rates of divorce, remarriages, along with blended families (that combine the nuclear families of the new couple), adoption of children, and one-parent families obscure caregiving standards regarding roles and responsibilities for elderly parents, step-parents, former parents-in-law, adopted parents, and grandparents, etc. So, too, there are no set standards for their adult children and grandchildren. Confusion can result in differing perceptions regarding roles and responsibilities, and increased tension and conflict can result between married couples, former spouses, children, and grandchildren.

There are also potential tensions between a spouse and in-laws. Notably discussed in Oriental and Indian cultures, studies have reported daughters-in-law neglecting mothers-in-law due to poor long-term relationships (Soeda & Araki 1999). It can only be assumed that a parent-in-law, perhaps living within the home of a daughter or son, might be especially vulnerable to acts of commission or omission by the son- or daughter-in-law in a failing marriage.

***Family Characteristics.*** It has long been known that some family members are inappropriate caregivers for relatives of any age; those who are psychopaths, substance abusers, inexperienced in caregiving, and

those who are unmotivated to provide care. Kosbera (1998) proposes careful screening to prevent placement of an elderly person into the care of such family members.

It is now known that an extensive family system may not be an effective caregiving system for an older relative. Fiore, Becker, and Coppel (1983) have discussed "family disharmony" resulting from conflict, disagreements, and anger between the members of a family system in the care arrangements for an older parent or other relative. Should one relative (such as an adult child) live with (or nearby) an impaired older person, while the other relatives live long distances away, the caregiver can feel disadvantaged. Arrangements can be made between relatives (such as siblings) to share the caregiving responsibilities for the older relative, if possible, or provide the caregiver either with periodic respite or with financial assistance. Yet, such arrangements may not exist. Caregiving family members may become angry with noncontributing relatives and take their hostility out on the dependent older care recipient.

As a childless spouse caring for an impaired husband or wife knows, similarly to a son or daughter without siblings, being the only caregiver to an older person places an undue burden on the caregiver who may have no one to share responsibilities. An older person being cared for by one person may be more vulnerable to undetected abuse committed by an over-burdened and angry caregiver. When other persons are involved, there is a greater likelihood that the caregiver will have to restrain himself or herself from abusing the older person, as well as have others to provide respite.

***Caring for Grandchildren.*** Resulting from such problems as parents seeking work or education elsewhere, or a result of other problems as AIDS, substance abuse, incarceration, mental illness, and marital breakups, is the possibility of grandparents caring for, if not raising their grandchildren. While such care has always existed in many countries, in other countries an increase in such caregiving responsibilities for grandparents seems unrelated to income level, urban or rural location, or age. With



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**Professor JORDAN I. KOSBERG Ph.D., ACSW**  
**Endowed Chair of Social Work, University of Alabama**

**BARBRA L. TORGUSEN MSW., CATSM**  
**Doctoral Student, School of Social Work**  
**University of Alabama U.S.A.**

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# THE FACE OF DEMENTIA

CHARLES SCERRI

“What is your name?” “Auguste.”  
“Last name?” “Auguste.”  
“What is your husband’s name?” “Auguste, I think.”

In 1901, a confused 51-year old female patient entered the Frankfurt Hospital for the Mentally Ill and Epileptics, where she was placed under the care of the attending physician and neuropathologist Alois Alzheimer. After several days of examination and attempted conversations with his patient, Alzheimer concluded that Auguste D. was suffering from cognitive impairment, speech and perception problems, delusions, and psychosocial incompetence. However, these typical symptoms of what was then termed senile dementia were occurring at an unusually early age, thereby warranting the diagnosis of presenile dementia. In the weeks and months that followed, the patient’s condition continued to deteriorate steadily, leading to her death within five years.

The keen observations by Alzheimer and others at the beginning of the 20<sup>th</sup> century did not occur in a historical vacuum. They were made at a time when the great epidemics of infection that had ravaged the cities of Europe and elsewhere for centuries were increasingly being brought under control as a result of public health measures and improvements in environmental conditions. Relieved from the burdens of struggling against recurrent epidemic illness, the newly developing medical sciences began turning their attention towards a more rigorous understanding of the fundamental mechanisms of disease. By the middle of the last century, numerous advances in diagnostic and medical treatment began to change profoundly the patterns of disease from acute infections such as tuberculosis and poliomyelitis to those involving chronic illnesses such as heart disease and cancer. This led the way to the development of effective drugs to treat heart conditions, high blood pressure and even some malignancies. This, coupled with improvement in surgical techniques, industrial safety, nutrition and personal lifestyle, has added at least 20 years to the average lifespan. This situation has now swung the

pendulum of disease even further towards chronic conditions associated with ageing such as cancer, degenerative joint disease, osteoporosis and the neurodegenerative disorders.

## The Age of Ageing

We are now living in a rapidly ageing world. The sharp rise in life expectancy, coupled to a steady decline in birth rates in all developed countries and in many developing ones, has led to the unprecedented demographic revolution characterised by an explosive growth in the numbers and proportion of older persons. According to estimates by the United Nations Population Division, the number of persons aged 60 years or older is expected to reach 2 billion by mid-century. Already today, the proportion of persons 60 years and older stands at 1 in 4 or 5 in many western European countries. Should present trends continue, this ratio is expected to reach 1 in 3, or even 1 in 2 by the year 2050. Among the aged, the oldest old (more than 80 years) constitute the fastest growing segment. As medical care and access to healthcare improve world-wide, the rate of population ageing will also accelerate rapidly. If global communication can be said to be ‘shrinking’ the world, then global ageing is surely ‘maturing it’.

## The Paradox of Time

The patterns of chronic illness that accompany old age have profound social and economic consequences for society as a whole and for healthcare systems in particular. It is therefore not surprising that age-related issues are increasingly becoming important on all national and international agendas. The old-age dependency ratio (number of working age individuals per older person) decreased from 12 to 9 between 1950 and 2002. If this trend continues, the ratio will plummet to just 4 by 2050. Such a change has major implications for social security systems in which the present workforce pays for the benefits of current retirees.



Similarly, medicine will be faced with the task of caring for an ever-older population whose chronic disabilities are more difficult to treat. The cost of care and therapy will be higher, partly because the disease remains with the patient forever. For the most part, medical interventions cannot actually cure chronic illnesses, but must continually treat and manage such conditions. Furthermore, older persons also tend to suffer from concomitant diseases. Thus, the paradox of time is that yesterday's hard-won achievements in healthcare have left us with tomorrow's more intractable dilemmas and challenges. Each improvement in healthcare also becomes more expensive.

Under the present circumstances, any diagnostic or medical intervention that can delay the onset or progression of chronic diseases and their associated costs will have enormous public health impacts. This is especially true in the area of dementia where diagnostic and drug costs are substantially lower when compared with the major long-term cost of institutionalisation. Given the fact that the prevalence of Alzheimer-type dementia increases exponentially from about 2-3 % of the population at age 65 to nearly 47 % after the age of 85, any interventions that slow down the rate of disease progression even modestly will have a major public health impact. For instance, delaying the onset of Alzheimer's disease today by 5 years would reduce the number of persons developing the disease in the United States by over one million by 2007.

Dementia is a serious, common, and rapidly growing world-wide problem associated with increased healthcare utilisation. It is a major predictor of morbidity and mortality in the elderly. The occurrence of the more than hundred known diseases that produce this condition depends on age, as well as genetic factors linked to geography, race and ethnicity. Dementia can be defined as a chronic deterioration in cognitive abilities (such as memory, attention, judgement etc.) that impairs the previously successful performance of activities of daily living. Whatever its specific cause, dementia results from a disruption of brain cells' functioning. Its profile and degree of severity are affected not only by the total quantity of brain cell loss, but by the specific location of the underlying brain damage. By far, the most common form of dementia is Alzheimer's disease which constitute about 40-60 % of cases. In developed and developing countries,

more than 33 % of women and 20 % of men over the age of 65 will develop dementia or milder forms of cognitive impairment in their lifetime.

There are other forms of cognitive impairment, some of which are reversible upon treatment. These include dementia due to vitamin deficiency, drug intoxication, alcoholism and endocrine disorders. Therefore the importance of accurate diagnosis is clear. However, this may prove to be difficult due to overlapping disease profiles, a problem very common in the elderly. Depending upon various scientific studies, the clinical diagnosis of Alzheimer's disease is reported to be correct only 63 to 90 % of the time.

### **Alzheimer's disease – the new pandemic**

Alzheimer's disease may be classified according to different criteria and can be categorised into two types: (i) less frequent inherited familial forms and (ii) the far more common sporadic type for which no obvious inheritance patterns have been established. The latter generally emerges after 65 years of age, and is thought to depend on various factors. Unfortunately, so far, there is no single assessment tool that is highly specific for the diagnosis of Alzheimer's disease and therefore different approaches are required. Ultimately, only autopsy can unequivocally differentiate between the various dementing disorders.

Growing at a rate that nearly rivals the AIDS pandemic of the late 20<sup>th</sup> century, Alzheimer's disease is an archetypical neurodegenerative malady. The insidious disease process, probably multifactorial, is thought to begin in a small area of the brain, referred to as the hippocampus, which is important in memory formation. From there, the damage spreads to other areas of the brain, reaching the cerebral cortex – the seat of language and reasoning. By contrast, areas that control the senses and movement are usually spared until late in the disease process. In those selective brain regions affected by Alzheimer's disease, brain cells gradually cease to function, lose their connections and eventually die.

### **Familial and sporadic types**

In the absence of a family history, the overall lifetime risk of developing Alzheimer's disease is about 10 to 12 %. Certain genetic factors, however, are associated

with an increased risk for its development and its rate of progression.

In recent years, mutations in certain genes have been identified as major risk factors for developing the rare, early-onset familial forms of Alzheimer's disease. In such cases, the condition is hereditarily transmitted to the offspring and in such cases, 50 % of the descendants will eventually develop the disease. Searching for these genetic abnormalities should be advocated for those families with a pattern of early-onset familial Alzheimer's disease, or when clinical suspicion of this possibility is high.

On the other hand, the sporadic type is usually not precipitated by genetic factors, although the presence of some genes has been implicated. Its cause depends on various components such as for example head injury. In both cases, most of the brain damage is caused by plaques and tangles, two abnormal structures that are the hallmarks of the disease.

### The different stages

Overall, the natural history of the disease can be characterised as an irreversibly progressive brain disorder that ultimately results in devastating memory loss, profound behavioural and personality changes, and severely damaged cognitive abilities. These impairments are related to the underlying death of brain cells and the breakdown of communication between them. The course of the disease varies individually, as does the rate of decline. On average, patients with Alzheimer's disease live for 8 to 10 years after they are diagnosed, although the disease can last from only 1 up to 20 years. Owing to the insidious nature of the disorder, the frequent confusion of early dementia with benign senescent forgetfulness, the fear of diagnosis, and the fatalism surrounding the disease, family members often do not bring the patient to medical attention in its initial phase.

The first stage of the disease is principally characterised by the decline of memory. During this period, symptoms are dominated by the loss of recent memory. Subtle but increasing signs of faulty judgement and personality change also occur during this stage. Individuals affected often tend to think less clearly and fail to recall the names of common objects and familiar persons.

In a second stage, as memory decline worsens, language, attention, calculation, and executive functions all become gradually impaired. During this phase, patients lose their ability to perform independently such simple tasks as dressing, washing and eating. In the final third stage, all cognitive functions deteriorate. Such persons are thereby bereft of all reasoning ability and end up being totally dependent on family or specialised personnel for everyday care. Finally, the disease is so debilitating that patients become mute, incontinent, and unable to walk or even stand. Now, permanently bedridden, they become increasingly prone to illness and infection. Most commonly, Alzheimer's disease patients die of pneumonia.

Given this inexorable dementing process, it is clear that an understanding of Alzheimer's disease is not only relevant for proper diagnosis, but also for the development of new drugs. Increased attention is especially being devoted to an improved understanding of the earliest stages of the disease, before brain damage is irreversibly severe and generalised, and when therapeutic interventions might be most effective.

Some 20 years ago, it was already apparent that Alzheimer's disease exhibited a complex clinical picture. Despite such diversity, it was soon realised that a standard set of objective criteria was urgently required for a more accurate diagnosis of Alzheimer's disease. Such a framework was also needed to provide a more rational means for carrying out investigative studies and clinical trials. Through the joint efforts of an expert working group convened by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA), the publication of what is known as the NINCDS-ADRDA criteria appeared in 1984. These criteria, widely used today, specify three levels of diagnostic certainty for Alzheimer's disease: possible, probable, or definite.

Soon afterwards, other equally valid sets of criteria for Alzheimer's disease were also formulated which today appear in the World Health Organisation's International Classification of Disease, tenth edition (ICD-10), and in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV). Not surprisingly, all three diagnostic frameworks share many common features. For



instance, they all require the presence of a dementia syndrome, with memory decline as a major feature of the clinical presentation. Additionally, all three stipulate that patients demonstrate impairment in at least one non-memory cognitive domain, and that such mental deficits not be confined to a delirious period. They all emphasise that other potential causes of dementia be excluded. Each definition insists that a gradually progressive course of disease be observed over time.

In the absence of a unique diagnostic marker for Alzheimer's disease, the assessment for patients suspected of having Alzheimer's disease is currently based on a broad, comprehensive work-up that consists of (a) a thorough clinical evaluation (including a physical exam and medication review); (b) a neurological examination involving psychological tests and possibly a brain scan; and (c) laboratory testing (for vitamin deficiency, folic acid levels, thyroid function etc.).

Neuropsychological screening tests are used to assess the general mental capabilities of a patient as well as provide meaningful information about the presence, type, magnitude, and quality of cognitive dysfunction. Some of the widely used cognitive tests include the Mini-Mental State Examination (MMSE), the Clock Drawing Test, and the Blessed Dementia Rating Scale. After initial screening, more comprehensive screening involving a battery of tests is often carried out. These include the use of CT and MRI scans.

### Limitations

Although the development and application of specific consensus criteria has substantially improved the diagnostic accuracy for Alzheimer's disease and other dementias, the sensitivity and specificity of these guidelines are imperfect. There is an undesirable degree

of variability and subjectivity and dependence upon clinical expertise. The identification of mixed dementia syndromes is unclear and a frequent source of error.

With respect to assessment tools, the outcomes of neuropsychological tests may be affected or even compromised by confounding factors such as old age, cultural background, language, education, sensory deficits, and concomitant psychiatric or general disease. Moreover, such assessments are often limited in their ability to distinguish between the different types of dementia due to overlapping psychological profiles.

### Treatment perspectives

Alzheimer's disease is thought to develop as a result of a complex cascade of events that occur over time in the brain. Although the precise mechanisms underlying the development of the disease remains to be elucidated, it is clear that brain degeneration leads to deficiencies in particular substances which play an important role in proper brain functioning. One of these is acetylcholine, a chemical associated with memory and attention processes. Since in Alzheimer's disease, there is lack of acetylcholine, one way to treat the underlying symptoms is by elevating acetylcholine levels in the brain. Other drugs currently available target other neurotransmitter systems implicated in memory.

Today, various drugs are used as an effective means to treat Alzheimer's disease. The goals of treatment are to reverse, stabilise or at least slow down the loss of memory and cognition associated with the disease, thereby allowing patients to maintain their functional autonomy for as long as possible. It is too early to talk about a cure, but these drugs, with all their modest benefits, have provided researchers with a major impetus for the development of new therapeutic approaches for Alzheimer's disease.

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**CHARLES SCERRI B. Pharm (Hons) M. Phil Ph.D (Dundee) CBiol MIBiol**  
**Department of Clinical Pharmacology and Therapeutics**  
**University of Malta**  
**charles.scerri@um.edu.mt**

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# Impacts of HIV/AIDS on the older persons in China

XU QIN - LU FAN - YUAN YE

**Abstract:** The HIV/AIDS epidemic in China has become widespread since the first HIV case detected in 1985. Up to now, the accumulated number of HIV infections and of AIDS patients has reached 840 000 and 80 000 respectively. The HIV infections in persons aged 50 and over compose about 10% of total HIV infections and are increasing rapidly. Former blood donation is the main route of infection of older persons with HIV. There are two pathways of AIDS affecting the older persons. One is direct infection with AIDS. The other, indirect, pathway is that older parents are affected since their adult children became persons With HIV/AIDS. Based on national AIDS surveillance data and in-depth investigation, this study first revealed epidemic trends of AIDS among older people aged 50 and over. We also discuss the living and psychological statuses and problems of the older persons with HIV/AIDS and HIV/AIDS parents, and the role of older parents to the life of their HIV/AIDS adult children in China.

## Population Ageing in China

According to the 5th Census in 2000 in China, the population of those aged 60 and over is up to 129.98 millions, 10.5 % of the total population. The population of aged 65 and over is 88.27 millions, 7.1 % of the total population. The population of aged 80 and over is about 13 millions, 1.0 % of the total population. 65.8 % of the older population aged 60 and over live in rural areas. The degree of population ageing in China will be enhanced more rapidly at the first half of the 21st century. Forecast by UN, the population aged 60 and over will comprise 30% of the total population and the population of 80 and over will be up to 7% of the total population in 2050.

## The HIV/AIDS Epidemic in China

The HIV/AIDS epidemic in China has changed substantially and the disease has become more widespread since the first HIV case detected in 1985. According to estimation by experts from the Chinese Centre for Disease Control and Prevention (CDC), the accumulated number of HIV infections and AIDS patients has risen to 840,000 and 80,000 respectively. Although the adult prevalence rate is less than 0.1 %, the epidemic has spread to all 31 provinces (autonomous regions and municipalities). The number of reported HIV/AIDS cases has

increased significantly. By the end of 2003, the cumulative number of HIV cases was 62159, mainly transmitted via blood— 74.1% of reported, cases. The main route is sharing injection equipment among IDUs, (51.2%), then Blood/plasma sale --- 21%, sex transmission ---7.5%, from mother to child ---0.4%, and unknown ways ---18.0%. A lot of people with HIV came forth because of illegal and nonstandard phlebotomizing in some provinces especially in the middle part of China about 1995.

## The Research in China and other countries

There are two basic routes of impact of AIDS on older persons: one is the direct effects of AIDS on their health and life quality after older persons themselves are infected by HIV; the other is indirect, the older generation relatives of adults who become ill with and died from AIDS are likely to be affected through multiple pathways on their emotional, economic, physical and social well-being. So, there are two types of older persons who were affected by AIDS: one type are the older person with HIV / AIDS, the other type is the older generation relatives (mainly older aged parents) whose children or younger generation are infected by HIV or ill with AIDS.

In different countries and regions, because of the



distinction of the politics, cultures. socio-economic development and prevalence of AIDS, the impacts and effects of AIDS on the older aged persons are different, and the research emphasis of this problem is different correspondingly. In U.S.A, the emphasis is mostly on the older aged persons with AIDS and the aged group with infection risk. In some countries of Africa and Asia, the study emphasis is on the economic, health, psychological effects of older persons whose adult children have AIDS, and the important role the older aged persons play in caring for the adult children with AIDS and supporting the orphans of AIDS patients. Until today, there is no study and investigation on the impacts of AIDS on the older population in China and this is the first specialized study.

### Method and data

To ensure the comparability of the research results, this study adopts 50 years as the starting age of the "older person", as is more often used in the literature and data sources in other countries and international organizations.

There are two methods adopted in this study, the macro quantitative analysis base on the national AIDS surveillance data and the micro individual analysis base on the results of individual interviews. The macro study will focus on the current prevalence situation and tendency of AIDS among the older population from the demographic and epidemiological perspective. The micro study will focus on life condition and concerns of those older persons who are affected by AIDS from the perspective of sociology, including the older persons with HIV/AIDS the older generation relatives (mainly older aged parents) whose children or younger generation are living with HIV/AIDS.

### The Individual Interview

Due to the limitation of time and funds, our study selected only village A and village B as the spot of in-depth investigation. We interviewed altogether 51 old people and 7 key informants in the case study. Among the 51 old people, there were 37 older generation relatives of those living with HIV/AIDS,

14 older persons living with HIV/AIDS themselves. There were 31 males and 20 females; the older stage of interviewees was 75 years old. 7 key informants were interviewed including 2 village cadres, 1 village accountant, 2 linkmen of the HIV persons, 1 medical staff and 1 relative of an HIV patient.

### Epidemical trend of AIDS among the older persons

*More than 10% HIV subjects are aged 50 and over, increasing rapidly.*

According to the annual case report in 2003, persons living with HIV who are over 50 compose 10.6% of the whole HIV cases. Among the AIDS patients, persons with AIDS who are over 50 form an even greater proportion – 17% and 16.6% of the AIDS deaths. If conservatively estimated at 4.1% of the HIV and 10.6% of the AIDS for persons aged 50 and over in 2001, there would be 34 thousand infected persons aged 50 and over among the infected 840 thousand. Among the AIDS patients totalling 80 thousands, there will be 8 thousand patients aged 50 and over.

According to the data from national sentinel surveillance, there were only 4.1% of all the HIV cases aged 50 or over in 2001, while it rose to 10.6% in 2003. A lot of old people with HIV were reported because of the illegal and non-standard phlebotomizing in some provinces about 1995, and now they come into the aged phase, which makes the percentage grow rapidly.

It has been considered that the AIDS problem had nothing to do with the old persons for a long time. But beyond expectation, the result shows that HIV prevalence rate had reached a high level among the older group.

### Former plasma donation is the main infection route

According to the 2003 annual AIDS report, former plasma donation is the main infection route by which the older group as well as young to middle age adults (15-49) got infected (40.5%). Among the older

persons who got infected, 72.5% of them are the former plasma donors. The proportion grew rapidly in the older group aged 50 and over, from 30.7% in 2001 to 72.5% in 2003. As the Chinese government pays more attention to blood safety and management, the transmission route of blood/plasma sale had been fundamentally controlled. In the coming years it will not be a great threat to the older people. The transmission routes for the older persons will turn to heterosexual contact and intravenous drug use.

### **Living conditions and problems of the older persons with HIV/AIDS**

#### *The deteriorated health*

The health condition of a person with HIV is linked with the infection duration. With time, the immune system and the health condition of HIV infected persons are getting worse. Among the older interviewees infected with HIV, 7.1% of them have no obvious symptoms, and 92.9% of them have some symptoms. In those two villages, some people infected with HIV have shown symptoms, and some have died of AIDS. 57.1% of the older interviewees with HIV/AIDS were undergoing some treatment. 14.3% of the interviewees received some treatment in the past but not currently. 28.6% of patients had never taken any kind of treatment. The reason for not receiving treatment is usually lack of money.

#### *Hardly-maintained minimum living expense*

Fatigue is a common symptom after infection with HIV, which affects working and daily life seriously. The average household income of the interviewees was 900 RMB in the last year. Subtracting the costs of farming, few net earnings are left, but the medical expenses are going up and up which makes life worse and worse. Among the interviewees, 38.5% of them have debts, below RMB 3000 Yuan (\$1 = 8 Yuan), and 53.8% have debts over 3000 Yuan. The maximum debt is up to 20,000 Yuan.

“Younger” old persons are still the major workers of the family. 78.6% of older interviewees infected with HIV are still working in the field or outdoor, but some of them can’t bear the heavy work, and

some have to have a rest when falling sick. They can hardly maintain their basic lives with the health conditions getting deteriorated. One interviewee said: “I have an 80 year-old mother, one son and one daughter, both of them unmarried. I have big medical expenses to cover. I have to work in the field to support my family.”

#### *Long-term depression*

The older persons with HIV/AIDS were in dread of the coming AIDS death. They hoped to survive, but they could not get necessary treatment without sufficient money. “I am afraid that I can not afford to see a doctor because I cannot get money from credit unions or others.” “I do not know how to treat this disease. I feel desperate.” Some older persons infected with HIV are prepared for death psychologically/“I don’t think too much. I just work and eat every day.” “I do not have many choices. If I have money, I will see doctors. If not, just stay at home/” “I won’t complain if the disease can not be cured since everyone will die sooner or later.”

### **Living Conditions of the older aged parents of children with HIV/AIDS**

According to the age distribution, the bulk of the HIV cases consisted of young to middle age adults. Among the cases reported in 2003, people aged 30-39 represented 39.0%, those aged 20 - 29 – 26.1%, 40 - 49 – 19.2%. So people from 20 - 49 added up to 84.3%. The fact tells that AIDS mainly affects older people indirectly. With the increasing number of young to middle age adults infected by AIDS, the number of older aged parents will increase in the future.

#### *Reduced living standards and increasing debts*

In the two villages, children getting infection lead to the apparent reduction of living standards of their aged parents. A study in Thailand shows the same, 52% of families that had experienced AIDS deaths deal with the difficulty by reducing their living expenses. And it was estimated that their expenses on foods and beverages had been reduced by 42%. Most older parents live frugally before the HIV



infection of their children. In order to support their children on medical and living expenses after getting infection, the older parents had to reduce their own foods and clothing costs, even to endure the occasional headaches and fevers without seeing doctors. Some older parents with difficulties can only afford steamed buns, water and occasional preserved vegetables for 200 days in a year.

Among the interviewed older parents, judged by their yearly household income, living conditions, and self-health conditions, 55.6% of them are in medium economic condition and 36.1% are in poor economic condition. Only 2.8% of the households can maintain average living standards. For the huge medical expenses, parents had to borrow money in order to save the life of their child. Some borrow from the relations. Some have no one to borrow from and have to apply for loans from local credit unions. It is estimated that each family that has children who died of AIDS usually has debts between 5000 and 6000 Yuan.

#### *Losing economic security for later life*

In China “young old” people are still working in rural areas. Among the 36 interviewed older persons, 29 of them make their living by working in the field, which counts 80.6% of all interviewees. Only 3 persons mainly depend on their children or grandchildren, and 3 persons depend on their older spouses. But when they can't work any more, as uncovered by the social security system, they have to depend on their children. After the onset of symptoms in young adults, these cannot take care of themselves, so they had to leave alone their older aged parents. Once they passed away, they lost reliable economic support having used up all their savings for medical expense of their AIDS children. A lot of older parents go back to work in the field to support their children and grandchildren after retirement.

#### *Suffering from high mental pressure*

AIDS not only pushes the older persons into deep economic disaster, but also brings huge emotional burdens and psychological depression. After the children are infected with HIV, the older aged

parents realize that their children will probably pass away before themselves. And some older persons have experienced the death of their AIDS children. To all of them, the most brutal thing in their lives is to see their own children die in front of them. One female interviewee confessed: “After I knew that my child got AIDS, I was in deep grief and worried about his life all the time. I cried for 3 months afterward.”

Having no money to treat the children and a huge economic burden also bring psychological depression. With limited information, older aged parents do not know how to treat the children with HIV/AIDS and they feel desperate for their children's life and health condition.

#### **Support giving to children with HIV/AIDS by older aged parents**

Survey results show that older aged parents provide positive economic and emotional support to their children with HIV/AIDS.

#### *Daily cares*

For taking care of the children with HIV/AIDS conveniently, the older aged parents lived together with their children again, or ate together but lived separately. Among the 36 households interviewed, 14 older parents live separately with their HIV/AIDS children, 21 live together.

The older aged parents provide various types of support (including daily life care and nursing) administer medicine and emotional comforting. Among the interviewees, over 60% of the older aged persons always accompanied their children with HIV/AIDS to see the doctor, over 65% of them bought drugs for their children, and over 65% of them helped with household work.

The supervisor from village A stated that AIDS patients are usually bedridden for about 3 - 4 months, and most older aged parents come to help out during the time. The older persons take care of them almost every day, such as cooking dishes, feeding, bathing, night care and looking after the grandchildren. The mother performed a more important role than that



lives by guaranteeing the basic living expenses and education opportunities. Fifthly, older people wished to get security on support when they will be too old to work, and good funeral arrangements after death.

### **Socio-economic impacts of HIV/AIDS on the older persons**

The impacts of HIV/AIDS on older persons have close relationships with the social culture and the economic development in China.

#### ***The direction shift of generation support***

The generational relationship is loose in developed countries, but in many developing countries, including China, the close connection among generations is a great characteristic. Because of the lack of formal support from society, the support from the children's family is very important for the elderly. In many developing countries, AIDS makes this generation relationship reversed, as well as generational support, the older aged parents being shifted from support and care receivers to givers. The supporting responsibility of young generations ceases to operate and the later life of older people faces a crisis.

#### ***The poverty aggravation of older persons***

As is shown in our survey, AIDS makes older aged parents lose the security of late life in the rural areas, they have to face poverty and instability and fall into the high-risk status. AIDS causes a vicious circle. People become infected with HIV because of poverty, then through the HIV infection poverty gets worse, moreover usually extreme poverty. After children were infected with HIV, the older parents could only use their small savings, sold their belongings or even borrowed money to pay for the treatment of their children. Many families had to sell out all the valuable belongings, even foodstuff. With heavy debt, they fall into poverty again, this will go with them till the end of life.

#### ***Older persons suffering social exclusion***

With HIV/AIDS, they are ashamed to tell families, friends and medical staff the truth and the diagnostic

result, because this will incur blame, discrimination and exclusion, losing self-respect and confidence, and even getting attacked. Because of discrimination, many people did not want to be tested in the county CDC, even when some symptoms appeared, and they did not want to tell anybody about their diseases. In our survey, only a few people told others. Many people did not go to the local CDC for examination, and instead they went to the nearby CDC and used faked names. Because of discrimination, HIV infectors and AIDS patients might intentionally conceal the actual situations, and this makes HIV infectors unintentionally increase the possibility of infecting others.

The existence of social discrimination also becomes the obstacle for older people affected by HIV/AIDS getting social support. The discrimination will only make them live in the disease and poverty situations, and they cannot get rid of it.

#### ***Old person doubly isolated in society***

When people become aged, they lose working ability and live at the edge of their society. Because of the HIV/AIDS crises, they become further emarginated. Most HIV/AIDS persons live in rural area and they are the most vulnerable group. Older persons affected by HIV/AIDS often live a miserable life because of the complex duties and roles. Director Shen Jie of National Center for AIDS/STD Prevention and Control said that HIV/AIDS is not a medical problem only, but a social challenge:

#### ***Policy supports and social care***

In the movement of controlling HIV/AIDS, the Chinese government has made serial policies, projects and activities, by which achievements are obtained. It has launched a programme, "Four Free and One Care" (CCTV International, April 12, 2004.) "Four Free and One Care" includes Free antiviral treatment for AIDS patients both peasants and the group with financial difficulty in urban areas; Free consultation and blood test; Free education for AIDS orphans; Free AIDS consultation, screening and antiviral treatment of pregnant women. Family members and communities build an amicable,

understanding, healthy living, working environment for persons with HIV/AIDS. All level government institutions gave necessary financing to the persons with HIV/AIDS according to regulations and supported actively the HIV persons who can take part in production. But there are no special policies and projects for the older aged persons. Many of these affected by HIV/AIDS need the basic economic, medical, psychological, mental, social and legal supports. Much promotion and education on HIV/AIDS is just focused on the population aged below 50, which puts the older aged persons outside those valuable activities.

Many international studies have shown that, we should sustain the older caregivers on health and capability, which will be applied for the younger family members infected with HIV/AIDS through the policies and projects from many departments. The action should emphasize on the three realms as follows: the first is to enhance the ability to care for the patients with HIV/AIDS and the orphans. The second is to ensure that the older aged persons live close; the third is to supply financial support to the older persons who are themselves affected with HIV/AIDS.

## CONCLUSIONS

For the first time, our study reveals the current situation and effects of HIV/AIDS among the older population, and shows the living conditions,

problems and needs of elderly people with HIV/AIDS (or whose children and younger relatives are infected) which specify the age structure through the epidemiological surveillance data and case studies of the highly infected community. The main conclusions are:

1. Young to middle age adults are the main body of HIV infection which determines that HIV/AIDS mainly affects older people indirectly.
2. The percentage of the older AIDS patients (aged 50 and over) in the total population is increasing rapidly, and plasma donation is the main spreading route by which the older group got infection.
3. Older aged persons with HIV/AIDS have deteriorated health conditions; they hardly maintain the minimum living expenses and suffer long-term depression.
4. The HIV/AIDS adult children bring their older aged parents negative impacts, through reducing of living standards increasing debts, losing economic security, and enduring high mental pressure.
5. HIV/AIDS changes family structure, the direction of generational support, and deepens the poverty of the older persons. HIV/AIDS makes the older persons suffer from exclusion, and makes those isolated doubly in society.
6. HIV/AIDS shifts the role of relationships. The older aged persons give many kinds of support to the adult children, becoming support givers instead of support receivers.

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**Professor XU QIN**  
**Research Scientist**  
**China Research Centre on Ageing**  
**E-mail: creaxuqin@yahoo.com.en**

**Dr. LU FAN**  
**Director of Department of Epidemics, CDC**

**Associate Professor YUAN YE**  
**China Research Centre on Ageing**

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# INTERNATIONAL DIARY 2005

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**May 7th - 8th - London, U.K.**

2nd Anti Ageing Conference London (AACL)  
Website: <http://www.antiageingconference.com>

**June 3rd - 6th - Oakland, California**

AGING; Mechanisms and Prevention  
Website: [www.americanaging.org/2005.html](http://www.americanaging.org/2005.html)  
E-mail: [julian@worldeventsforum.com](mailto:julian@worldeventsforum.com)

**June 15th - Washington, DC**

AARP One-Day Conference: Universal Village:  
Livable Communities in the 21st Century.  
Website: [www.aarp.org.livable](http://www.aarp.org.livable)

**June 26th - 30th - Rio de Janeiro, Brazil**

World Congress of Gerontology (IAG)  
Website: [www.acceventos.com.br](http://www.acceventos.com.br)

**June 27th - 29th Trondheim, Norway**

Sixth International Conference - Creative Solutions  
for an Ageing Society: Sharing the Wisdom  
Website: [www.iahsa.net](http://www.iahsa.net)

**June 29th - July 1st, Russian Federation, Moscow**

ISSA 11th International Conference on Information  
and Communication Technology in Social Security  
Website: [www.radissonsas.com](http://www.radissonsas.com)  
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**September 5th - 9th - Buenos Aires, Argentina**

International Forum of the Social Science - Policy  
Nexus.  
Website: [www.unesco.org/shs/ifsp](http://www.unesco.org/shs/ifsp)  
E-mail: [ifsp@unesco.org](mailto:ifsp@unesco.org)

**September 20th - 24th - Stockholm, Sweden**

12th Congress - International Psychogeriatric  
Association Aging with Dignity - new challenges -  
new possibilities - new solutions  
Website: [www.ipa-online.org](http://www.ipa-online.org)  
E-Mail: [ipa@2005@congrex.se](mailto:ipa@2005@congrex.se)

**September 29th - October 1st St. Gallen, Switzerland**

1st World Ageing & Generations Conference  
Website: <http://viva50plus.org>  
E-Mail: <http://viva50plus.org>

**September 30th - October 2nd - Ljubljana, Slovenia**

XVIII International EURAG Congress 2005  
Website: [www.eurag.europa.org](http://www.eurag.europa.org)

**October 5th - 7th - United Kingdom**

British Geriatrics Society Autumn Meeting  
Harrogate International Centre, UK  
Website: [www.bgs.org.uk](http://www.bgs.org.uk)  
E-mail: [bgs@hamtonmedical.com](mailto:bgs@hamtonmedical.com)

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## INIA'S ACTIVITIES 2005

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**17th - 18th May** Un Economic Commission for  
Europe (UNECE) Task Force Meeting, (MALTA)

**19th - 29th May** Workshop on **CARE PROVISION  
IN AGEING SOCIETIES: WHAT ARE THE  
POLICY CHALLENGES AND HOW TO  
ADDRESS THEM**, organised by the UN Economic  
Commission for Europe (UNECE) and the  
International Institute on Ageing (INIA), (MALTA)

**16th - 27th May**

International Short Training Programme in  
**GERIATRICS**, (MALTA)

**21st - 30th May**

Short Training Programme in **SOCIAL AND  
HEALTH ASPECTS OF AGEING** in collaboration  
with the Beijing Civil Affairs Bureau.

**September**

In-Situ Training Programme in **GERONTOLOGY** in  
collaboration with the Singapore Action Group of  
Elders (SAGE), (SINGAPORE)

**October 2005 - June 2006**

International **POST GRADUATE DIPLOMA IN  
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European Centre of Gerontology and Geriatrics,  
(University of Malta), (MALTA)

**October**

In-Situ Training Programme in **GERONTOLOGY** in  
collaboration with the Beijing Civil Affairs Bureau  
(BCAB), (HUAIROU)

**7th - 18th November**

International Short Training Programme in  
**DEMOGRAPHIC ASPECTS OF POPULATION  
AGEING, POLICIES AND ITS IMPLICATIONS  
FOR SOCIO-ECONOMIC, POLICIES AND  
PLANS**, (MALTA)

**5th - 16th December**

In-Situ Training Programme in **GERONTOLOGY  
AND GERIATRICS** in collaboration with Caisse  
Nationale de Securite Sociale (CNSS), Tunis (Tunisia)