



Human Rights Council**Eighteenth session**

Agenda item 3

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Thematic study on the realization of the right to health of
older persons by the Special Rapporteur on the right of
everyone to the enjoyment of the highest attainable standard
of physical and mental health, Anand Grover***Summary*

In the present report, submitted in accordance with Human Rights Council resolution 15/22, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, considers the realization of the right to health of older persons.

Noting the significant pace of the world's ageing, the study urges a paradigm shift according to which society should move beyond a simple search for healthy ageing by its citizens and begin working towards active and dignified ageing, which is planned and supported just like any other stage of the individual's life course. Active and dignified ageing for older persons requires reframing society's concept of ageing to put more focus on the continued participation of older persons in social, economic, cultural and civic life, as well as their continuous contributions to society.

The report underlines that the right-to-health approach is indispensable for the design, implementation, monitoring and evaluation of health-related policies and programmes to mitigate consequences of an ageing society and ensure the enjoyment of this human right by older persons. Accordingly, health facilities, goods and services should be made available, accessible, affordable, acceptable and be of good quality for older persons.

The report also notes that encouraging older persons to remain physically, politically, socially and economically active for as long as possible will benefit not only the individual, but also the society as a whole. It further concludes that the promotion and protection of human rights of older persons should be of concern to everyone because ageing is a process that will apply to all.

Contents

	<i>Paragraphs</i>	<i>Page</i>
I. Introduction	1-4	3
II. Ageing a shifting paradigm.....	5-18	3
III. The right to health of older persons	19-33	7
IV. Specific issues and concerns	34-70	10
A. Primary health care and chronic illness	35-43	10
B. Long-term care.....	44-53	12
C. Palliative care.....	54-60	14
D. Informed consent	61-69	16
IV. Conclusions and recommendations.....	70-71	18

I. Introduction

1. At its fifteenth session, the Human Rights Council in its resolution 15/22 requested the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, to prepare a thematic study on the realization of the right to health of older persons, including the main existing challenges and best practices, with the assistance of the Office of the United Nations High Commissioner for Human Rights and in consultation with States, relevant United Nations agencies, national human rights institutions and other relevant stakeholders.

2. In February 2011, the Special Rapporteur invited States, relevant United Nations agencies, national human rights institutions and other relevant stakeholders to submit information and comments that would inform him on the main existing challenges and good practices on the realization of the right to health of older persons.¹ The Special Rapporteur expresses his appreciation for the high level of participation by States and other stakeholders in what is often perceived to be a complex and marginal area in human rights.

3. On 7 April 2011, the Special Rapporteur convened an expert meeting on the right to health of older persons in Geneva. During the meeting, a number of prominent experts on ageing, the health of older persons and health-related human rights had focused discussions of challenges posed by ageing and explored measures to address them from a human rights perspective. The main issues that were considered during the consultations related to primary health care and chronic illnesses; legal capacity and informed consent; palliative care; and home support and institutional care.

4. On 8 April 2011, the Special Rapporteur held a public consultation on the right to health of older persons in Geneva, which was organized by the Office of the United Nations High Commissioner for Human Rights (OHCHR) and attended by representatives of nearly 30 States and international organizations. During the public consultation the Special Rapporteur shared his initial remarks and main observations from the expert meeting, and engaged in an open dialogue with States and other relevant stakeholders on the realization of the right to health of older persons.

II. Ageing: a shifting paradigm

5. The world population is ageing at a steady and significant pace. The total number of persons aged 60 years and above increased from 200 million in 1950 to 760 million in 2010, and it is anticipated to become over one billion by the end of the current decade.² By 2050, it is expected that one in five persons will be over the age of 60.³ The senior population is the fastest growing one and this is becoming a global phenomenon.

6. Although the growth of the older population is affecting the whole world, most of the increase is taking place in the developing world. More than half of the elderly (400 million) live in Asia, while Europe is the region with the second-largest number of older persons (nearly 161 million), followed by North America (65 million), Latin America and

¹ In order to increase the outreach, the invitations were circulated both through notes verbales and through a public announcement posted on the OHCHR homepage of the Special Rapporteur, which allowed for direct electronic submissions.

² *World Population Prospects: The 2008 Revision*, vol. II: Sex and Age Distribution of the World Population (United Nations publication, Sales No. 10.XIII.3).

³ World Health Organization, *Social Development and Ageing: Crisis or Opportunity?* (WHO, Geneva, 2000), p. 4.

the Caribbean (59 million), Africa (55 million) and Oceania (5 million).⁴ On average, it is estimated that 29 million older persons will be added to the world's population each year between 2010 and 2025, and over 80 per cent of those will be added in the developing countries.⁵ By 2050, it is further projected that around 80 per cent of the elderly will live in the developing world.⁶

7. The Special Rapporteur considers these compelling figures a harbinger of a quiet demographic revolution. It owes much to the significant gains achieved in many areas which have substantially increased longevity but will have far-reaching and unpredictable consequences for all countries, developed and developing alike. A rapidly ageing population presents significant challenges for the global community, in a world that is already affected by various social, economic, cultural and political challenges. The immediate consequences of longer life expectancy include increases in the prevalence of chronic and non-communicable diseases and disabilities, which, if unaddressed, could place significant burdens on health systems, strain pension and social security systems, increase demand for primary health care and put pressure on the availability and affordability of long-term care.

8. Developing countries will be predominantly affected by the resulting epidemiological transition, when non-communicable diseases amongst older persons increase. The broader population will however continue to struggle with communicable diseases, particularly infectious diseases and other illnesses related to poverty. Developing age-friendly services and settings, and promotion of health care and preventive medicine among older persons will strengthen the efforts of developing countries to deal with the complications of chronic and terminal non-communicable illnesses. In order to address the challenge adequately, it is essential for States to prepare themselves to meet the needs of older persons, train health professionals in old-age care, and formulate sustainable policies for long-term care.

9. However, the ageing world's most important challenge is to ensure the enjoyment of human rights of older persons. It is critical that measures be put in place to eradicate discrimination and exclusion of older persons and to ensure access to services according to their needs. In a statement marking the International Day of Older Persons, the United Nations High Commissioner for Human Rights, Ms. Navi Pillay, pointed to the urgent need for better legal protection of older persons, a growing sector of society that is often most vulnerable and neglected, and she emphasized that "the human rights community has been slow in realizing that the global agenda and the advocacy efforts at the national level can no longer ignore the rights of older persons".⁷

10. The Special Rapporteur believes that the right-to-health approach is indispensable for the design, implementation, monitoring and evaluation of health-related policies and programmes to mitigate consequences of an ageing society and to ensure the enjoyment of this human right by older persons. Such an approach to health-related issues includes human dignity, the needs and rights of this vulnerable group, and puts emphasis on ensuring that health systems are accessible, available and affordable to all. Integrating human rights into

⁴ Follow-up to the Second World Assembly on Ageing: comprehensive overview, Report of the Secretary-General (A/65/157), 21 July 2010, para. 4

⁵ Follow-up to the Second World Assembly on Ageing: comprehensive overview, Report of the Secretary-General (A/65/157), 21 July 2010, para. 5

⁶ 10 Facts on Ageing and the Life Course, WHO Fact File, available at WHO homepage <http://www.who.int/features/factfiles/ageing/en/index.html>.

⁷ "Millions of older persons are denied their rights", Statement of the United Nations High Commissioner for Human Rights on 1 October 2010 <http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=10402&LangID=E>.

health systems also means ensuring the principles of equality and freedom from discrimination and the empowerment of all, including the poor, allowing for their participation in decision-making processes and incorporating accountability mechanisms which they can access.

11. The Special Rapporteur believes that the promotion and protection of human rights of older persons is not only in the interest of senior persons, but should also be of concern to everyone, because every person ages. The right to health will not provide a magic solution to these multifaceted challenges, but it will allow shifting the discourse on older persons from a needs-based approach to a rights-based one, and enable greater articulation of the rights of older persons. Health is a fundamental human right, indispensable for the exercise of many other rights. It is necessary for living a life in dignity. This is especially true for older persons, who are often perceived as a “lapsed” segment of society and are particularly vulnerable to infringements of their right to health.

12. The Special Rapporteur concedes that in order to be fully successful the right-to-health approach to older persons should be accompanied by a paradigm shift with respect to how society perceives ageing and older persons. The World Health Organization defines ageing as the “process of progressive change in the biological, psychological and social structure of individuals”.⁸ Throughout the course of one’s life, the human body’s functional capacity declines from early adulthood to old age. However, increases in longevity also mean that older persons may stay active for a longer part of their lives than ever before, both in terms of occupational and non-occupational activities. Encouraging older persons to remain physically, socially and economically active for as long as possible will have benefits not only for the individual, but for society as a whole.

13. The Special Rapporteur believes that the dominant view, which considers ageing a biomedical problem, leads to the unfortunate perception of ageing as an abnormal or pathological phenomenon because it equates advanced age with illness. This position is not only inconsistent with the holistic approach to human health, but it also perpetuates a perception of older persons as dependent and sick. When considering the health of older persons, the Special Rapporteur is of the view that there must be a paradigm shift away from the perception of older persons as a “social burden” to one that emphasizes the process of “active ageing” and that will reorient our ideas about ageing to focus on the continuing contribution of older persons to society. According to WHO,⁹ active ageing aims to optimize opportunities for health, participation and security amongst older persons in order to enhance their quality of life. The word active therefore refers to continuing participation in social, economic, cultural and civic affairs, and not simply the ability to be physically active or to participate in the labour force.

14. Ageing should be perceived as the culmination of a lifetime of influences and choices. Healthy and active ageing occurs through health promotion and consistent delivery of primary health care throughout one’s life. The enjoyment of the right to health is not age-dependent and does not cease once a person reaches a certain age. Older persons should be viewed as rights-holders, who will often require support in order to claim their rights. This requires States to take particular steps as part of the development and implementation of comprehensive health plans that must include various strategies to ensure that older persons have access to good quality health care, goods and services. In addition to this, economic accessibility to ensure affordability is also required by the right to health, which requires that States take steps to ensure that adequate social protection is provided to older persons.

⁸ World Health Organization, *A life course perspective of maintaining independence in older age* (WHO, Geneva, 1999), p. 4.

⁹ “Active ageing: a policy framework”, WHO, April 2002, WHO/NMH/NPH/02.8.

The ageing of world population demands that immediate steps be taken to ensure that the costs of pension schemes and their analogues not be prohibitively burdensome for States. Failure to recognize older persons as rights-holders may lead to prejudice and discrimination directed against individuals or groups and may have profound consequences for their health outcomes and welfare.

15. Treating older persons as a homogenous group is incorrect and needs to be rectified. In developing a more comprehensive approach to the enjoyment of the right to health of older persons, it is important to both collect and analyse disaggregated data and develop appropriate strategies for diverse groups.

16. When appropriate, clinical trials should be conducted with the participation of older persons in order to determine the effect of these medications on that population group, due to the frequency with which older persons may use these medications. Given the substantial underrepresentation of older patients in studies on various diseases, clinical trial recruitment should be diversified to include a number of considerations including age, gender and race.

17. Differences between the genders in respect of the ageing process must also be acknowledged, given that global life expectancy at birth for women is currently 70 years, and is significantly higher than for men at 66 years.¹⁰ Given differing life expectancies, it is more often men who are able to rely on informal care from their spouses than women. Women who outlive their husbands are more often left with no spousal support, relying on informal care by other relatives or the formal care system.¹¹ Compounding this problem is the fact that older women are frequently excluded from social security and health insurance schemes that are linked to formal, paid employment. They are also at much greater risk of poverty than men. In many countries older women are less likely than men to hold valuable assets in their own name (A/HRC/14/31, paras. 19-21). These factors limit women's ability to provide for their own health-related needs in later life. Furthermore, lack of access to health care services for debilitating diseases such as cancer and hypertension, or illnesses disproportionately affecting women such as osteoporosis, have also been noted to prevent older women from enjoying their full human rights (CEDAW/C/GC/27).

18. The Special Rapporteur believes that States should allocate more resources for the provision of geriatric healthcare in order to ensure that all healthcare workers, irrespective of specialty or profession, are adequately trained to deal with the particular health issues associated with ageing. They should also be trained on the right to health so that they interact with elderly patients in an appropriate, considerate and non-discriminatory manner.

III. The right to health of older persons

19. The right to the highest attainable standard of health is a fundamental human right, legally enshrined at the international, regional and national levels. The enjoyment of the right to health is recognized by numerous international human rights instruments, including those that have been created to protect the human rights of particular groups, such as children, women, persons with disabilities and those who are subject to discrimination on the basis of race (E/CN.4/2003/58, paras. 10-21). The most important formulation of the right to health is contained in article 12 of the International Covenant on Economic, Social

¹⁰ WHO, *World Health Statistics* (WHO, Geneva, 2010), p. 56.

¹¹ WHO and The Institute for Alternative Futures, *A long-term care futures toolkit* (Geneva, WHO, 2002), p. 21.

and Cultural Rights, which provides the cornerstone protection of the right to health in international law.

20. Internationally recognized human rights standards and principles as contained in core international human rights treaties cover and protect older persons. Despite this tacit protection, it has increasingly been argued that there is a gap in the international human rights system because there is currently no specific universal human rights instrument on the rights of older persons. Specific provisions focusing on older persons, such as those which exist for some other categories of vulnerable persons such as women, children, persons with disabilities, and migrant workers, are also lacking.¹²

21. Nonetheless, different human rights treaty monitoring bodies have interpreted and applied existing norms to older persons as a group, recognizing their vulnerability to discrimination and exclusion. In 1995, the Committee on Economic, Social and Cultural Rights (CESCR) adopted general comment No. 6, which offers a detailed interpretation of the specific obligations of State parties regarding each of the rights contained in the International Covenant on Economic, Social and Cultural Rights, as they apply to older persons.¹³ In 2010, the Committee on the Elimination of Discrimination against Women adopted general recommendation No. 27 on older women and the protection of their human rights.¹⁴ General comment No. 14 of CESCR elaborates on substantive issues arising from the implementation of the right to health and addresses particular issues related to older persons, including “preventive, curative and rehabilitative health treatment...maintaining the functionality and autonomy of older persons ... [and] attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity”.¹⁵

22. In addition, there are non-binding United Nations instruments and international documents on ageing and older persons, such as the 1982 Vienna International Plan of Action on Ageing, the 1991 United Nations Principles for Older Persons, the 1992 Global targets on ageing for the year, and the 1992 Proclamation on Ageing. The most recent of these is the Political Declaration and the Madrid International Plan of Action on Ageing adopted at the Second World Assembly on Ageing in April 2002, and endorsed by the General Assembly in resolution 57/167 of 18 December 2002. The Political Declaration reaffirms the global commitment to promote and protect human rights and to eliminate age-discrimination, neglect, abuse and violence (art. 5). It further makes reference to the right to health (art. 14), the opportunity to work and the continuing access to education and training programmes (art. 12). It has guided the development of legislation and policies at the national level and provided a framework for international cooperation, which resulted in, among other things, the establishment of the Open-Ended Working Group on the Human Rights of Older Persons in 2010, pursuant to General Assembly resolution 65/182.

23. General comment No.14 describes legal obligations of States. The three primary obligations are to respect, protect and fulfil the right to health. The obligation to respect refers to the States’ duty to refrain from interfering directly or indirectly with the right to health. In many cases, older persons are the object of State policies which may infringe

¹² “Human Rights of Older Persons: International human rights principles and standards”, OHCHR Background Paper for Expert Group Meeting on 25-26 May 2010, p. 3, available on <http://www.ohchr.org/Documents/Issues/OlderPersons/OHCHRPaperHROlderPersons30062010.pdf>

¹³ See Committee on Economic, Social and Cultural Rights, general comment No. 6, “The economic, social and cultural rights of older persons” (E/1996/22, 8 December 1995).

¹⁴ See Committee on the Elimination of Discrimination against Women, General Recommendation No. 27, “Older women and protection of their human rights” (CEDAW/C/GC/27, 16 December 2010).

¹⁵ Committee on Economic, Social and Cultural Rights, general comment No. 14, “The right to the highest attainable standard of health” (E/C.12/2000/4, para. 25, 11 August 2000.).

upon their right to health. Examples include restrictions on the autonomy of older persons in terms of definitions of capacity without an individual determination. The obligation to protect deals with States' duty to prevent third parties, such as corporations, from interfering directly or indirectly with the right to health. This may be relevant, for example, where there is systematic abuse of the elderly in private long-term care facilities. Finally, the obligation to fulfil requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to fully realize the right to health.

24. According to general comment No. 14, the right to health contains both freedoms and entitlements. The freedoms include the right to make independent decisions about one's health, which is to say freedom from State interference. For older persons, freedoms regard issues such as informed consent, autonomy and guardianship. Entitlements, which concern positive obligations of the State may, for example, include the provision of primary health care and social protection which recognizes and takes into account age-related elements, States should recognize that ageing is a lifelong process; State policy and legislation should reflect this reality. Investment in health services should be made at various stages of the life course, when risks to well-being and windows of opportunity are greatest.¹⁶

25. Under the right-to-health framework, health facilities, goods and services should be made available, accessible, affordable, acceptable and be of good quality for older persons. Availability refers to the fact that functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity. In many cases, older persons are affected by selective unavailability because of rationing of medical care, i.e. allocation and prioritization of health resources, which often results in de-prioritizing older persons for health treatment. Accessibility includes physical, financial and information components. Older persons may be unable to access health care because of the location of services or their limited physical mobility. Poverty may also exacerbate older persons' inability to access healthcare, particularly where social security does not exist. Finally, information accessibility refers to the right to seek, receive and impart information regarding health issues. With regard to older persons, it means that health-related information should be tailored to suit their needs and communicated to them in an appropriate, comprehensible manner allowing them to make fully informed decisions about their health condition and treatment.

26. States should take measures to ensure that older persons receive age-friendly health care of a quality commensurate with that of other age groups. Examples of improved quality goods, services and facilities for older people would include greater numbers of geriatricians and improved training in geriatrics across all specialties to ensure that needs of older persons are recognised and attended to. There is also a need for improved communication across specialties, including allied health professions such as dentists, pharmacists etc in order to adequately address the treatment needs of older persons with multiple chronic illnesses.

27. General comment No. 14 notes that the right to health should be understood in broader terms, which include the underlying determinants of health, such as access to water and sanitation, food and nutrition, education and housing. An example of this would be the sub-optimal nutrition of older persons, which is commonly linked to circumstances under which older persons are isolated, immobile and live in poverty. Education is another relevant determinant for the health of older persons. A recent study in the United States of

¹⁶ *Women, ageing and health: a framework for action: Focus on gender*, Geneva, WHO, 2007. Accessed at: <http://www.who.int/ageing/publications/Women-ageing-health-lowres.pdf>

America showed that older persons with limited literacy had a higher risk of death, compared to those with adequate literacy.¹⁷

28. International human rights law proscribes discrimination and ensures equality on a number of grounds and for a variety of groups, including older persons. Older persons are further identified by general comment No. 14 as a group especially vulnerable to violations. Treaty bodies, including CESCR, have identified older persons as a vulnerable or marginalized group, one that is potentially more susceptible to discrimination and violence.¹⁸ According to general comment No. 14, it is important to ensure the functionality and autonomy of older persons (E/C.12/2000/4, para. 25). This implies promotion of individual choice with respect to models of care, insofar as this is possible.

29. Older women are often more disadvantaged because they may suffer from a combination of both gender and age discrimination. Ageing women make up a significant proportion of the world's population, with the majority of older women living in developing countries. A number of life-course events adversely affect the health of women in older age, including discrimination against infant girls in the provision of food and care, barriers to education, low incomes and poorer access to decent work, care-giving responsibilities as mothers and wives, domestic violence (during childhood, adulthood and elder abuse), widowhood, and cultural traditions and attitudes towards health care.¹⁹ Lower incomes, disruptions to work due to family responsibilities, and discrimination in access to the labour force during women's working life mean that women often have less retirement savings and are therefore more financially vulnerable in older age.

30. The right-to-health requires active and informed participation in policy decisions by those populations that are affected by them (E/CN.4/2006/48, para. 25). Effective provision of health services can only be assured if the participation of affected populations is secured by States (E/C.12/2000/4, para. 54). It is notable that the United Nations Principles for Older Persons encourages the participation of older people in the formulation and implementation of policies which affect them.

31. The Special Rapporteur notes the importance of monitoring progress in ensuring progressive realization of the right to health of older persons using indicators and benchmarks as part of the right to health framework. General comment No. 14 identifies the failure of States to monitor the realization of the right to health at the national level, as well as the resulting insufficient or misallocated expenditure, as examples of violations of the State's obligations (E/C.12/2000/4, para. 52).

32. Accountability is one of the central features of the right to health. It requires effective, transparent and accessible monitoring and accountability mechanisms. Accountability requires the incorporation of continuous monitoring into all aspects of policy development and implementation.²⁰ In the context of the right to health, accountability is the process that provides individuals and communities with an opportunity to understand how the government has discharged its right to health obligations, while providing the government with the opportunity to explain what it has done and why (A/63/263, paras. 8-

¹⁷ Sudore et al. "Limited literacy and mortality in the elderly: the health, aging and body composition study", *Journal of General Internal Medicine*, vol. 21, No. 8 (2006).

¹⁸ See E/C.12/2000/4 and E/1996/22. For a more comprehensive list of where age has been recognized as a vulnerability, see: OHCHR, *Human Rights of Older Persons: International Human Rights Principles and Standards: Background Paper Expert Group Meeting* (OHCHR, Geneva, 2010).

¹⁹ WHO, *Women, ageing and health: a framework for action: focus on gender* (Geneva, WHO, 2007). Accessed at: <http://www.who.int/ageing/publications/Women-ageing-health-lowres.pdf>

²⁰ Helen Potts, "Accountability and the right to the highest attainable standard of health", University of Essex, 2008, p. 13, and see report of the Special Rapporteur (E/CN.4/2003/58, para. 59).

18). There are many different types of accountability mechanisms, including national human rights institutions, health commissioners, democratically elected local health councils, public hearings, patients' committees, impact assessments, judicial proceedings and others (see A/63/263, para. 11). And when mistakes have been made, accountability requires redress.

33. Any person or group victim of a violation of the right to health should have access to effective judicial or other appropriate remedies at both national and international levels. The Committee on Economic, Social and Cultural Rights reiterated the importance of redress by noting that all victims of such violations should be entitled to adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of non-repetition (see E/CN.4/2003/58, para. 59).

IV. Specific issues and concerns

34. In addition to the broad issues with respect to the right to health framework outlined in the previous section, there are a number of specific issues and concerns relevant to older persons that require a more detailed assessment. This section will consider some of those issues: primary health care and chronic illness; long-term care; palliative care; and informed consent as related to older persons, including guardianship issues.

A. Primary health care and chronic illness

35. WHO defined primary health care in 1978 as "essential health care; based on practical, scientifically sound, and socially acceptable method and technology; universally accessible to all in the community through their full participation; at an affordable cost; and geared toward self-reliance and self-determination".²¹ The defining features of primary care - continuity, coordination and comprehensiveness - are well suited to manage chronic illness, although more remains to be done to ensure that care of sufficient quality is provided.²² WHO noted the importance of incorporating evidence-based, cost-effective primary and secondary prevention interventions into the health system, with emphasis on primary health care,²³ which is the most appropriate forum through which these can be integrated.

36. Chronic illnesses and disability increase in prevalence with advancing age. Around half of deaths due to non-communicable diseases occur in persons aged over 70.²⁴ It is estimated that 35.6 million people lived with dementia worldwide in 2010, which will increase to 65.7 million by 2030 and to 115.4 million by 2050.²⁵ In light of the increasing proportion of the population who are elderly, it becomes vital that these conditions are managed in an equitable and resource-effective manner. Health systems throughout the world are generally designed to deal with acute medical conditions. They have struggled to re-model and adapt to prevent or manage the increasing number of chronic illnesses. One

²¹ Alma Ata Declaration, 1978, part VI.

²² Arlyss Anderson Rothman and Edward H. Wagner, "Chronic illness management: what is the role of primary care?", *Annals of Internal Medicine*, vol. 138, No. 3 (February, 2003), p. 256.

²³ WHO, *2008-2013 Action plan for the global strategy for the prevention and control of non-communicable diseases* (Geneva, WHO, 2008), p. 16.

²⁴ WHO, *2008-2013 Action plan for the global strategy for the prevention and control of non-communicable diseases* (Geneva, WHO, 2008), p. 9.

²⁵ Alzheimer's Disease International, "World Alzheimer Report 2010: The Global Economic Impact of Dementia", p. 2

should also note the importance of the use of evidence-based guidelines and establishment of minimum standards of health care for common chronic conditions, and integration of their management into primary health care.

37. The Committee on Economic, Social and Cultural Rights reiterated that primary health care essentially falls under the core obligations accrued by States in fulfilling the right to health (E/C.12/2000/4, para. 43). General Comment 14 places special emphasis on the care of older persons as a vulnerable group, which requires an “integrated approach combining elements of a preventative, curative, and rehabilitative health treatment” (ibid, para. 25). It also specifies that such measures ought to include periodic check-ups and measures aimed at maintaining physical and psychological functionality. Thus, the right to health requires a constellation of activities, programs, and interventions to address primary health care of older persons as a core obligation under that right. Improving availability, accessibility, acceptability and quality of primary care is essential in particular in achieving better results in the management of chronic illnesses.

38. Several obstacles have been identified in relation to older persons’ access to primary health care and to the quality of health-care services provided. Discrimination against older persons on the basis of their age is a major barrier to access primary care and prevention of chronic illness. . There is a pernicious and deeply ingrained notion that once a person ages, he/she becomes incapable of contributing to society, chronically ill and/or frail. Such prejudices often lead to a conclusion that not much can be done to assist them.

39. It is essential that the actual vulnerabilities of older persons are recognized, and prejudicial perceptions and attitudes are addressed, so that goods and services are designed in such a manner to overcome actual, rather than perceived, barriers in accessing healthcare. Discriminatory attitudes of medical professional towards older persons could also undermine meaningful communication with their patients with direct consequences on the accuracy of diagnosis and quality of treatment.

40. Access to primary healthcare services is also impeded by both physical and financial obstacles. Healthcare facilities might be situated too far from older persons’ place of residence, with transport proving to be too expensive, inadequate, or simply unavailable. Compounding this problem is the limited mobility of older persons. They may be unable to drive, have no access to transportation, or have physical impairments that reduce their movement. Physical difficulties to access health for older persons are further reinforced by their socio-economic vulnerability, especially as access to health care is often subject to receiving a pension or to paying out-of-pocket fees. Living in poverty can also be a root cause of deterioration of older persons’ health: with limited access to safe drinking water or adequate nutrition, older persons face a high risk of contracting diseases. Even where health services are accessible to older persons, they are not always adapted to their needs.²⁶

41. Improving the quality of care provided by primary care physician to older patients remains a challenge which is exacerbated in rural areas, where rural general medical practitioners have fewer opportunities to partner with geriatricians to deliver care to their catchment area. Dissemination of information from specialty areas into primary care should be encouraged in all areas, but is particularly important in respect of older persons, given the suitability and cost-effectiveness of the management of chronic diseases within the primary care setting.

42. It is also important that primary care and prevention of chronic illness is promoted and strengthened in the developing world. A paradigm shift is necessary to detect diseases early and mitigate their effect, rather than wait until the onset of health problems. More

²⁶ World Health Organisation, “Towards age-friendly primary health care”, 2004, p. v

needs to be done to stress the importance of prevention efforts, regular contact with a general practitioner or other primary health-care provider, and early diagnosis and treatment. Prevention is extremely important, as it allows reaching the individual before the disease takes hold. It needs to be emphasized that early diagnosis and prevention, long before a person grows older and preferably at the primary health-care facility, is one of the key elements in ensuring good health in old age.

43. Due to resource constraints, particularly in developing countries, “best-practice” care may not always be possible. This should not deter States from taking steps to achieve the best possible outcomes for older patients in any given situation. Moreover, it has been acknowledged that personalization of care may, at times, require eschewing of more intensive services and accepting clinical outcomes that are less than the best possible health and function.²⁷ Although this may still look like an anathema to some medical professionals, a shift in focus from curing to caring, particularly in older population, could be necessary to better meet the patient’s personal goals. Presenting patients with options and ensuring that their desired outcomes are achieved through collaborative decision-making should be paramount in the professional-patient relationship.

B. Long-term care

44. Long-term care includes a variety of services (medical or otherwise) that help meet both the medical and non-medical needs of people with a chronic illness or disability who cannot care for themselves for long periods of time. Long-term care is manifested in the provision of help with daily tasks such as bathing, dressing up, cooking and so on. According to the Organization for Economic Cooperation and Development (OECD), long-term care can be defined as “a range of services for people who depend on ongoing help with the activities of daily living caused by chronic conditions of physical or mental disability”.²⁸ In the context of the right to health, long-term care must also be understood as the intervention of skilled practitioners to provide assistance in dealing with syndromes associated with chronic diseases or disabilities impeding personal capacities. They are, nonetheless, medical conditions affecting older persons disproportionately.

45. Long-term care takes two broad forms: home care and institutional care. Institutional care is the accommodation and care of a person in a specialized care-giving institution. Older persons in such institutions are often under the authority of the caregiver, who is meant to assist them in their daily activities, including the administration of medicines and health services. Given the growth of such institutions, it is important to examine implications for older persons and their right to health.

46. Home care is generally understood as medical services performed by professionals in the patient’s home, as opposed to care provided in specialized institutions. It generally allows older persons a greater degree of autonomy over their lives than institutional care. However, home care should be understood as medical home care delivered by health professionals, as opposed to informal care that is provided by family members or other individuals.

47. It is essential that appropriate recognition be given to those who care for older persons in informal settings, which has both benefits and risks. Informal care may allow older persons to remain in their homes, and be cared for by a familiar person, an option

²⁷ David B. Reuben, “Better Care for Older People with Chronic Diseases” *JAMA* vol. 298, No. 22 (December, 2007), p. 2673.

²⁸ OECD, *Long-term Care for Older People* (OECD, Paris, 2005), p.3

often preferred by the patient. It also reduces reliance on formal or institutional care, minimizing the burden on these limited resources. However, older persons are often placed, or find themselves, in informal care without a thorough assessment, exposing them to risk. Such risks include inadequate care by a person who is not equipped to provide the necessary care, as well as the risk of abuse by a caregiver. Numerous States have introduced initiatives to provide support to carers, such as financial support in lieu of lost income, and respite care, which allow older persons to stay at home as long as possible, whilst receiving good-quality care.²⁹

48. Formalized long-term care of both types is already prevalent in much of the developed world. In the developing world, traditional social dynamics are also undergoing changes due to various globalizing factors. Families play a steadily less prominent role as primary health-caregiver of older persons, and government institutions and medical professionals are assuming a bigger role in care-giving. The situation is exacerbated in developing countries by the lack of adequate institutional mechanisms and absence of measures to protect the rights for older persons in the context of external and non-family care. Developed countries, where infringements on the rights of older persons also take place, feature only relatively better in developing such mechanisms.

49. The Special Rapporteur stresses the impact of institutionalization on the autonomy of older persons and its often harmful effect on their dignity. Loss of full independence, restricted freedom of movement and lack of access to basic functions would cause feelings of deep frustration and humiliation to any individual. Older persons are no exception to this. It is essential that complaints mechanisms are put in place to address practices that unnecessarily restrict liberty and autonomy of older persons and to enable them to reclaim their dignity.

50. The Special Rapporteur is particularly concerned about unreported violence directed against older persons in care. As with other vulnerable and marginalized groups, special attention is needed to protect older persons from abuse and to ensure that their rights are not violated in settings where they might be especially prone to violations. Abuse of older persons is defined as a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.³⁰ It is important to note that abuse is often insidious, limiting the autonomy of older persons in subtle ways. It can take various forms, including physical, psychological, emotional, sexual or financial abuse, or be affected by neglect.

51. The abuse of older persons can be complex when the abusing caregiver is a relative or a family member. The frequency of elder abuse in the domestic setting, including abuse perpetrated by family members, was estimated by one study as occurring in anywhere between 2 and 10 per cent of all cases. In an institutional setting incidences of abuse are even harder to ascertain. Abuse may also take the form of prejudicial and discriminatory attitudes and acts, which manifests itself through paternalism towards older persons in care, leaving them feeling humiliated, infantilized, and robbing them of the identity they otherwise have as human beings.

52. In some instances, health-care workers themselves may not even recognize instances of abuse. Health-care workers should therefore be trained and assisted in identifying possible cases of abuse. Models of such training and intervention are used in cases of domestic abuse and may serve as workable models for dealing with recognition and treatment of the abuse of older persons. Health-care workers need to become aware of the

²⁹ OECD, *Long-term Care for Older People* (OECD, Paris, 2005), p. 11-12.

³⁰ WHO, *The Toronto Declaration on the Global Prevention of Elder Abuse* (WHO, Geneva, 2002), p. 3.

possibility that a patient may be a victim of abuse and be able to manage health-related interactions, in a way which would make the abused individuals feel comfortable discussing their particular situation.

53. Various initiatives have been adopted in the area of domestic violence, particularly in respect of violence towards women, which could be drawn upon to raise awareness of abuse of older persons amongst medical professionals and the wider community. In addition to increased training, procedures need to be put in place for reporting abuses and addressing the consequences. For example, the 2006 Older Persons Act of South Africa, inter alia, requires a person who may witness the abuse of an older person, not only physical but also psychological, sexual, and economic abuse, to report the violation. The Act also establishes a system in which abusers of older persons are investigated and registered with a view to prohibiting them from operating or being employed in a residential facility or community-based care for older persons.

C. Palliative care

54. General comment No. 14 states that measures should be taken to ensure attention and care for those who are chronically and terminally ill, sparing them avoidable pain and enabling them to die with dignity (E/C.12/2000/4, para. 25). Palliative care is the primary approach, from a health perspective, of seeking to improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering.³¹

55. Palliative care has grown significantly in the last 30 years and is progressively implemented within national health systems, although this has been done to varying extents. The wide range of measures taken in different States shows the growing importance of ensuring quality of life of older persons towards the end of their lives and providing support for their families. In some countries palliative care is recognized only in the context of certain chronic diseases such as cancer. Other States have integrated palliative care into their national health legislation and plans of action and created institutions which are devoted to palliative care. Some other countries have placed obligations on health institutions to have staff qualified in palliative care or have established group of experts on the issue.

56. Several issues arise with respect to the provision of palliative care to older persons, one of which concerns availability of palliative care and in particular, medicines utilized in such care. Moderate to severe pain is a common by-product of illnesses requiring palliative care, for which opioid-based analgesics are commonly prescribed.³² State parties to the International Covenant on Economic, Social and Cultural Rights are required, as a core obligation under the Covenant, to ensure provision of essential drugs as defined under the WHO Action Programme on Essential Drugs. Despite this and the fact that oral morphine and other narcotic preparations are inexpensive and should not be difficult to obtain, the availability of such medications used in palliative care is often limited. That is due to a number of factors, such as restrictive drug regulations, failure to implement a properly functioning supply and distribution system, and inadequate health-care system capacity. Particularly concerning is the complex international narcotic control framework that severely inhibits access to medicines regulated under the framework.³³ Even when such medications are available, there often remains a lack of understanding of palliative care and

³¹ WHO, *WHO Definition of Palliative Care* (Geneva, 2010). Available from www.who.int/cancer/palliative/definition/en/

³² WHO, *Pain Relief Ladder* (Geneva, 2010). Available from www.who.int/cancer/palliative/painladder/en/.

³³ See A/65/255, Section V: "Access to controlled medicines".

the use of narcotics in pain relief amongst medical practitioners. More comprehensive training on palliative care and the use of narcotic drugs is needed. These barriers to availability of good quality palliative care are not unique to older persons as a group, but older persons are disproportionately affected due to the increased incidence of chronic and terminal illness amongst them.

57. Older persons may also be less likely to receive palliative care services than other, younger age groups. More research is needed to determine whether this distribution is inequitable or whether the needs of older persons are being met through other services.³⁴ The right to health clearly proscribes discrimination in respect of age, including within palliative health care services. States are obliged to respect the right to health by refraining from denying or limiting equal access for all persons to palliative health services (E/C.12/2000/4, para. 34). Age-based discrimination that is sanctioned on the basis of risk/benefit profiling cannot under any circumstances be considered appropriate in the context of palliative care, which aims to improve quality of life, rather than its length.³⁵

58. The biomedical approach to ageing, combined with increased longevity, has resulted in additional ethical dilemmas. The increasing difficulty or impossibility of refusing life-extending interventions has been seen as a challenge confronting both patients and medical practitioners, which has been linked to three factors: the gradual move away from “choice” about interventions towards routine treatment; the connection of clinical interventions with expressions of care; and the increasing availability of interventions creating high expectations in respect of health outcomes, which results in blurring of the boundaries between curative interventions and those which simply prolong life.³⁶

59. The Special Rapporteur is of the view that a holistic approach to health should also address the process of dying. While this report does not consider issues of patient autonomy in respect of deciding to end life, it is nonetheless necessary to ensure that patients be able to make autonomous, informed decisions regarding the quality of health during the process of dying. That includes choices about access to adequate pain relief and other necessary interventions, location of death, and the ability to refuse treatment designed to prolong life when it is not desired by the patient. This requires clear, candid and non-judgmental discussion with medical practitioners, who should be adequately trained to deal with these delicate issues in order to enable older persons to “die with dignity”, as required from a human rights prospective.

60. The Special Rapporteur believes that the end of life of persons forms an integral part of their life. Consequently, he stresses that older persons must be treated with as much dignity during the process of dying as they should have been in the earlier phases of their life course. Palliative care requires important funding and mobilisation of numerous actors and stakeholders within the medical sector, and it is absolutely crucial in order to prolong the lives of older persons affected by life-threatening diseases and to ensure their death in dignity.

³⁴ Jenni Burt & Rosalind Raine, “The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review” *Age and Ageing* vol. 35, No. 5 (September 2006), pp. 471 and 473.

³⁵ Jenni Burt and Rosalind Raine, “The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review”, *Age and Ageing*, vol. 35, No. 5 (September 2006), p. 469.

³⁶ Sharon R. Kaufman, Janet K. Shim and Ann J. Russ, “Revisiting the Biomedicalization of Aging: Clinical Trends and Ethical Challenges” *The Gerontologist*, vol. 44, No. 6 (December 2004), p. 732.

D. Informed consent

61. Guaranteeing informed consent is a fundamental feature of respecting an individual's autonomy, self-determination and human dignity. Informed consent invokes several human rights elements that are indivisible, interdependent and interrelated. In addition to the right to health, these include the right to autonomy, freedom from discrimination, freedom from non-consensual experimentation, security and dignity of the human person, recognition before the law, freedom of thought and expression and reproductive self-determination. Individual autonomy, bodily integrity and well-being are central to the right to health framework. This framework identifies the availability, accessibility, acceptability and quality of health information as key elements of that right, defined as "the right to seek, receive, and impart information and ideas concerning health issues" (E/C.12/2000/4, para. 12). In a report to the General Assembly, the Special Rapporteur defined informed consent as "a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers" (A/64/272, para. 9).

62. Health information needs to be of the highest quality, freely available on a non-discriminatory basis, accessible to the individual's particular communication needs (including special physical or cultural circumstances), and presented in a manner culturally and otherwise acceptable to the person consenting (*ibid.*, para. 23). Informed consent requires that communication is cognizant of varying levels of comprehension and not be too technical, complex, hasty, or in a language, manner or context that the patient does not understand. This is particularly true and necessary for vulnerable populations, such as older persons, who may require additional attention, explanation, or assistance in receiving and adequately understanding the health information that is imparted by the caregiver to the patient prior to treatment.

63. Evaluations have consistently found a deficit in the information provided to older persons to help them make an informed decision, in particular those with less formal education.³⁷ Some healthcare workers can be dismissive of the particular vulnerabilities of older persons, failing to adequately obtain informed consent because it may be more complex than usual to do so. A one-size-fits-all approach is often inappropriate with respect to older persons. A more customized, individualized, age-friendly approach is required to better address the needs of this group. This will imply moving beyond basic health literacy, which does not adequately secure the right to health, into greater health information awareness and education, possibly through peer networks.

64. In addition to the imbalance of power, experience and trust inherently present in the doctor-patient relationship, structural inequalities can result in the voluntary or informed nature of consent being significantly compromised (*ibid.*, para. 45). With a view to protecting the rights of older persons, States should establish appropriate support mechanisms that would help overcome subsequent challenges to achieving informed consent, including community involvement and comprehensive counselling.

65. The role of health-care providers is crucial for ensuring informed consent. In many cases, there is a lack of training for health-care workers in communicating health information to older persons, who may have special needs that are often left unaddressed. Medical education and training institutions must incorporate education regarding informed consent for vulnerable populations and their particular needs into curricula. Structural

³⁷ Sugarman et al., "Getting meaningful informed consent from older adults: a structured literature review of empirical research", *Journal of the American Geriatrics Society*, vol. 46, No. 4 (April 1998)

problems further frustrate efforts to obtain informed consent, such as the amount of time available to doctors and health-care workers to consult with patients. Older persons may require additional attention and assistance to fully understand the implications of the health-related information with which they are presented and which may render them particularly affected by scarcity of available consultation time. In general, each person should receive an individualized treatment, and his/her state of health should be regularly reviewed, including his/her medication.

66. Persistent denial of the right to informed consent could constitute a form of physical and psychological abuse of older persons, who are much more prone to treatment and care without consent. This is compounded by discrimination directed against older persons, who in some cases may have a diminished capacity to consent to treatment. The Special Rapporteur previously pointed out that older persons are taken advantage of due to perceived ignorance and helplessness, as well as actual physical or mental frailty such as that caused by degenerative diseases resulting in decreased ability to provide informed consent (A/64/272, para. 51). They face more frequently situations in which informed consent is necessary, and the possibility of infringement and abuse is therefore greater.

67. Domestic jurisdictions often fail to enact legislation or design policies in order to address and resolve problems particular to informed consent and older persons. The problem of legislation on older persons and the right to health is particularly acute in developing countries, which often lack an adequate legal framework concerning guardianship or consent. In some countries, the legal requirement for informed consent is circumvented by guardianship proceedings even in partial incapacitation, replacing patient's consent with that of the guardian. The right to health requires that States respect, protect, and fulfil the right to health, and it is incumbent upon States to develop policies and frameworks through which the right to health of older persons can be addressed to meet these requirements. It is important to establish safeguards to ensure the informed consent of older persons in the context of guardianship and build the capacity of older persons to fully understand and make use of health information.³⁸

68. The Special Rapporteur believes that the issue of informed consent of older persons is increasingly important given global ageing and the consequent societal challenges. He further believes that international guidelines and national systems should be developed to regulate practices and ensure that older people are supported in making informed health-care decisions. It is also desirable to establish peer groups who would provide older persons with information before their visit to a doctor or other care provider for treatment, which might help overcome immediate problems such as lack of training.

69. The Special Rapporteur points to the importance of increasing awareness and empowering of older persons in order to strengthen their participation in health policymaking and build networks of older persons through which health information can be more easily accessed. It is also important that older persons are in a position to fully understand health information and make voluntary and informed decisions based on that information. It is the duty of the State to find and implement new and innovative ways to reach out to older persons, identify age-friendly means to disseminate health-related information and encourage their participation.

³⁸ Convention on the Rights of Persons with Disabilities, arts. 12(3) and (4).

V. Conclusions and recommendations

70. In a report of this length, it is impossible to address all of the important issues, but the Special Rapporteur notes with urgency the present demographic changes leading to a rapidly increasing number of older persons. Society should move beyond seeking simply healthy ageing for its citizens, and begin working towards active and dignified ageing, which should be planned and supported just like any other stage of the individual's life course. Planning for old age implies putting in place diagnostic and prevention services at the primary healthcare level long before ageing sets in. The pursuit of active and dignified ageing for older persons requires re-framing society's concept of ageing to focus on the continued participation of older persons in social, economic, cultural and civic affairs, as well as their continuous contributions to society longer into their lives. The promotion and protection of the human rights of older persons should be of concern to everyone because ageing is a process which everyone will undergo. Older persons are especially vulnerable as a group because of stereotyped perceptions of the group as a "lapsed" segment of society. However, as life expectancy increases and medicine improves, older persons stay active longer than ever before, both in terms of occupational and non-occupational activities. Encouraging older persons to remain physically, politically, socially and economically active for as long as possible will benefit not only the individual, but also the society as a whole.

71. The Special Rapporteur recommends:

(a) Recognizing ageing as a lifelong process, a reality which State policy, legislation and resource allocation should reflect so that health-care services, including diagnostic and prevention services, are available and accessible to a person before becoming old to allow for healthy ageing;

(b) Ensuring that the right to the highest attainable standard of health shapes, and is integrated into, relevant national and international policies concerning ageing and older persons. Health facilities, goods and services should be made available, accessible, affordable and acceptable to older persons, and be of good quality;

(c) Implementing the right-to-health framework to ensure shifting the discourse surrounding older persons from a needs-based perspective to a rights-based approach, which enables greater realization of the right to health of older persons;

(d) Encouraging the establishment and support of networks of older persons in order to ensure their participation in the development and improvement of social protection and health care, which recognizes and ensures the enjoyment of the right to health;

(e) Establishing a system of social protection that affords older persons access to long-term care, whether institutional or home-based, which ensures that abuse or violations of rights do not take place;

(f) Putting in place policies and procedures for reporting, addressing and preventing abuse of older persons;

(g) Instituting mechanisms to raise awareness and train medical professionals, non-medical carers and the wider community on the treatment of older person, and to prevent and address their abuse;

(h) Developing international guidelines and national systems to regulate and monitor hospice-care practices to ensure that the elderly are supported in making

informed health-care decisions, and that their human dignity and autonomy are not neglected due to their vulnerability

(i) Establishing and implementing safeguards to ensure that free and informed consent is required for any treatment and/or other medical intervention and that this is guaranteed for all patients, no matter their age, condition and treatment proposed;

(j) Developing and implementing mechanisms to protect the rights of older persons if/when they are deemed incapable of providing informed consent to any treatment and/or other medical intervention due to injury, disease or chronic conditions such as dementia.
