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REVIEW ARTICLE

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# World psychiatric association section of old age psychiatry consensus statement on ethics and capacity in older people with mental disorders

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## SUMMARY

The World Psychiatric Association (WPA) Section of Old Age Psychiatry, since 1997, has developed Consensus Statements relevant to the practice of Old Age Psychiatry. Since 2006 the Section has worked to develop a Consensus Statement on Ethics and Capacity in older people with mental disorders, which was completed in Prague, September 2008, prior to the World Congress in Psychiatry. This Consensus meets one of the goals of the WPA Action Plan 2008–2011, “to promote the highest ethical standards in psychiatric practice and advocate the rights of persons with mental disorders in all regions of the world”. This Consensus Statement offers to mental health clinicians caring for older people with mental disorders, caregivers, other health professionals and the general public the setting out of and discourse in ethical principles which can often be complex and challenging, supported by practical guidance in meeting such ethical needs and standards, and to encouraged good clinical practice. Copyright © 2009 John Wiley & Sons, Ltd.

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## INTRODUCTION

This consensus document continues the series of previous WPA Section of Old Age Consensus Statements as well as of the Section's activities since 2006 in the field of ethics. It also contributes to the WPA's work on ethics across mental health, in particular the Declaration of Hawaii/II (World Psychiatric Association, 1983), the Madrid Declaration on Ethical Standards for Psychiatric Practice, (World Psychiatric Association, 2005) and the WPA Statement and Viewpoints on the Rights and Legal Safeguards of the Mentally Ill (World Psychiatric Association, 1989). The Consensus Group met in Prague, Czech Republic, in September 2008 to develop this statement. The meeting was organised by the WPA Section of Old Age Psychiatry, with the participation of International Council of Nurses, Alzheimer Europe and Alzheimer Disease International. Participants who are recognised for their expertise in this area came from 11 countries and include psychiatrists, a neurologist, a nurse and family caregiving representatives.

The aim of this Consensus Statement is to provide a practical tool to assist all those involved on ethical issues. It is addressed to health and social care practitioners, trainees, professional organisations, older people, their families and carers, NGOs and other advocacy groups, healthcare commissioners and policy makers as well as to the general public. The provision of high-quality care to older people with mental illness raises complex ethical problems; for example, guiding decision making around transfer from independent to institutional care and in the allocation of scarce health resources. Mental health professionals have a particular responsibility to ensure that older people with mental health problems are involved to the maximum degree in decisions about their treatment and care, to safeguard their patients' rights and to combat ageism and elder abuse. Its objectives are to promote debate at all levels on these ethical issues, to describe the main contexts where the provision of high-quality care to older people with mental illness raises complex ethical problems, to inform practice and training and to encourage effective advocacy.

In this document, the term 'mental illness' refers both to the dementias and to the range of psychiatric disorders in old age, as has been the case in previous Consensus Statements established by the Section (World Health Organization/World Psychiatric Association, 1996, 1997, 1998, 2002). Old age has been defined by convention as referring to people who

have reached retirement age (World Health Organization/World Psychiatric Association, 1996) but this document is also relevant to younger people with dementia since in some countries their needs are met by old age services.

## ETHICAL PRINCIPLES

At all times practitioners should act to respect the dignity and personhood of older people with mental illness. The content of this document is guided by universal ethical principles; these rarely operate in isolation. Although many difficult ethical decisions involve conflicting principles, reasonable resolution is possible.

### *Respect for autonomy*

This is the need to respect an individual's right to self-determination and the decisions they make regarding their health and social care, provided they have capacity to do so. The aim of mental health interventions for older adults is to preserve and enhance their personal autonomy. Respect for autonomy should be universal, although the decision process to ascertain capacity may vary from state to state.

For example, provided they have capacity, individuals should be able to choose whether they want to take tablets for depression.

### *Beneficence/ non-maleficence*

Beneficence is the requirement to consider the potential benefits arising from a course of action and balancing these against the potential risks. Clinicians should always act for the benefit of patients. Non-maleficence is the requirement not to cause harm.

For example, the clinician providing the tablets for depression should be satisfied the tablets are likely to be effective and take steps to minimise any potential harm.

### *Justice*

Justice refers to the need (at local and Government levels) to ensure equitable distribution of resources, and to treat all patients equally.

For example, all patients with depression should have equal access to treatment irrespective of their age and circumstances.

### Veracity

Clinicians should be honest with patients who have the right to know (or not to know) their diagnosis and be given accurate information when they request it.

For example, when a clinician starts treating a patient for depression, s/he should inform the patient of the diagnosis, prognosis and benefits/risks of the proposed treatment.

### HUMAN RIGHTS FOR OLDER PEOPLE

There are existing frameworks outlining Human Rights Principles for Older People (United Nations, 1991) and for people with a mental illness (World Health Organization, 2005). Health professional organisations have also developed ethical codes of practice that embody ethical principles and human rights. As far as we know there are no published Human Rights frameworks specifically for older people with mental health problems. Such a framework is however necessary in view of the special vulnerability of this population by virtue of societal ageism, stigmatisation, exclusion as well as the disability and dependency which mental illness in old age may confer.

The following values should underpin any such framework

- Independence. Older people with mental disorders have the right to contribute usefully to society and to make their own decisions on matters affecting their life and death
- Safety and dignity. Older people with mental disorders have the right to live safely, with adequate food and housing, free of violence, abuse, neglect and exploitation
- Care and treatment. Older people with mental disorders should benefit from family and community care and protection and have access to healthcare to help them maintain or regain their optimum level of function and well-being and prevent or delay deterioration.

### AGEISM, DISCRIMINATION AND STIGMATISATION

This Statement affirms the principles enunciated in a previous WHO/WPA Consensus Statement (World Health Organization/World Psychiatric Association, 2002).

The following definitions underpin these principles.

*Stigma* results from a process whereby certain individuals and groups are unjustifiably rendered shameful, excluded and discriminated against.

*Discrimination* is any distinction, exclusion or preference that nullifies or impairs equal enjoyment of rights.

*Ageism and age discrimination* describe attitudes and practices that disadvantage older people.

Older people with mental illness may experience the double jeopardy of stigmatisation due to psychiatric illness and due to being old. In some countries, older women may face further stigmatisation because of their gender. Poverty may lead to even further discrimination. The need to reduce stigma and discrimination is ethically mandated by their harmful consequences including perpetuation and worsening of mental illness (World Health Organization, 2005). Neither chronological age nor dementia (or mental incapacity) should in itself be a reason to withhold beneficial treatment of psychiatric or physical conditions. Overall resource shortage does not justify discrimination against older people with mental illness.

### CONFIDENTIALITY

Individuals have the right to expect that information about them should be treated confidentially. Confidentiality should be protected in people who lack capacity unless there are overriding concerns regarding their welfare or the safety of others. The degree of any breach of confidentiality must be proportionate as well as necessary. The degree of acceptable disclosure to family members varies across cultures.

For example, if a patient with psychosis asks a clinician not to disclose details of the diagnosis or treatment to anyone, the clinician should maintain confidentiality except where the safety of another person may be at risk as a result of the psychosis.

### ELDER ABUSE

Older people with mental health problems are at high risk of abuse. There are many forms of elder abuse including psychological, physical, sexual, financial and social abuse as well as neglect and abandonment. Elder abuse is often hidden and under-reported. It is incumbent upon all those involved in the care of vulnerable elders to be vigilant for signs of abuse and for carers to recognise that carer stress may reduce their threshold for perpetrating abuse.

Abuse should never be condoned whatever the mitigating circumstances. What may not be considered abusive towards a healthy, competent person may be so in a vulnerable older adult. Adequate staff

numbers, appropriate training, fair pay and recognition, and defined career structures are essential in reducing risk of elder abuse as is enhanced public awareness and education.

## DECISION-MAKING CAPACITY

Most jurisdictions have legal frameworks to protect people with impaired decision-making ability. While separate definitions for the terms 'capacity' and 'competence' have been proposed, in practice they are often used interchangeably to mean sufficient ability to make informed decisions. Neither age nor a diagnosis of a mental disorder is sufficient in itself to determine lack of capacity.

The presumption of capacity is an important legal principle, though in some jurisdictions the presence of severe mental disorders may reverse this presumption. It is important to emphasise that capacity is specific to (a) the decision in question (e.g. decisions on health care, writing wills, dealing with finances) and (b) its complexity (e.g. an individual may have capacity to consent to take simple analgesics for headache but not have capacity to consent to have electro convulsive therapy). Capacity may also change over time and context. Good clinical practice requires a flexible and supportive approach in order to optimise capacity.

Most health and social care professionals working with older people will have to make some type of capacity assessment and therefore require appropriate training. Expert advice may be needed by those with responsibility for formal adjudication of capacity in accordance with local custom and legal requirements.

Older people who are competent to make decisions have the right to refuse treatment which they believe would compromise their quality of life. Individuals need to be given adequate information in a suitable form about the decision in question. The information should include the patient's condition, the potential benefits and risks of the proposed course of action, and the alternatives and their potential consequences. Key components of capacity include understanding, appreciation, reasoning, retention and the ability to express preference with consistency. The fact that a person is making an unwise or seemingly irrational decision (for example, by going against medical advice) does not in itself make the person incompetent.

The capacity to manage financial and personal affairs is determined by the local legal framework informed by a comprehensive clinical and functional assessment including but not restricted to cognitive assessment.

## *Substitute decision-making in personal, healthcare and financial matters*

Substitute decision making (SDM) arrangements range from the informal de facto surrogate through proxies appointed by the care recipient when still competent (including Powers of Attorney) to those who are Court-appointed. The terms 'guardianship', 'advocacy' and 'protective or financial management' have different meanings in different jurisdictions but usually imply the appointment of a legally appointed SDM for personal, health care and or financial matters. The European Dementia Consensus Network has provided helpful guidance (European Dementia Consensus Network Consensus Statements). Key recommendations are incorporated below.

People with limited capacity should be allowed to make those decisions, which they remain competent to make for themselves. Substitute decision-making should be invoked only as a last resort and be limited to areas over which an individual lacks capacity. Less restrictive approaches to the management of personal and financial affairs, such as the appointment of a Power of Attorney, should always be considered.

SDM should not imply automatic loss of other legal rights (e.g. voting, making a will or getting married). Appropriate measures should be taken to ensure and maintain discretion and respect for the privacy and human dignity of adults with SDM. The incapacitated person should be involved as much as possible in the choice of substitute decision maker. In the case of Court-appointed SDMs, the person with incapacity should be heard by the judge or equivalent authority imposing a substitute decision-making order.

SDMs should be obliged to take into consideration the wishes of the incapacitated person. This should include previously expressed wishes (as reported in advance directives or made known by significant others). The person should be kept informed of and consulted on decisions being made on his/her behalf even when deemed mentally incapable.

SDM measures and actions must be in the interests of the incapacitated person and their continuing necessity should be reviewed regularly. The management of financial assets should be for current benefit of the person under SDM and any conflicts of interest should be resolved.

Mechanisms should be in place for appeal and for review as well as for the reporting of alleged mistreatment by SDMs. It is recommended that legally-appointed SDMs be recognised in other countries except where this would contravene the laws of either country. These recommendations would be facilitated by wider



ratification of the Hague Convention on the International Protection of Adults (REF).

### *Decision-making and relationships*

The decisions of older people with mental illness may be influenced by their relationships and conversely, mental illness may affect a person's decision making in regards to forming or severing relationships. The right to form relationships, including sexual relationships is a fundamental human right into which courts, family and health and social care professionals should not interfere unless the exercise of that right involves abuse, neglect or exploitation. The key aim is to promote autonomy and to ensure safety within relationships.

Deciding to enter into a relationship is obviously a personal decision that normally does not require any formal test of capacity. However, questions of ability to consent or the possibilities of abuse sometimes arise when older people with mental illness enter into or maintain relationships and health care practitioners are sometimes asked to assess or intervene in such situations. Considerations to be taken into account when deciding whether or not to intervene in a possibly abusive relationship involving an older person with impaired capacity include comprehensive assessment of personal relationship background and life history. Specific questions to be considered might include:

- What kind of relationship do the two people have? Is there a power imbalance or element of coercion?
- Is there a significant discrepancy between the two people's cognitive capacity?
- What pleasure (or benefits) does the vulnerable person experience in the relationship? Are they willing or content for it to continue?

Relationships also may provide opportunity for undue influence over an older person's decision making. Those working with older people with mental illness should be mindful of the potential for influence by others who seek to persuade mentally ill impaired individuals to make decisions or execute legal documents in their favour.

In addition to promoting safety within relationships, this statement affirms the widely acknowledged importance of social support in the lives of mentally ill elderly and the role of support organisations. Carers themselves require support and the integrity and well-being of the care recipient often relies on the well-being of the carer. Particular difficulties may arise when the health and decision-making capacity of the carer (who is often the proxy decision-maker) is compromised.

### END OF LIFE ISSUES

Dementia is a terminal illness. People with dementia have similar end-of-life needs to those with terminal cancer and should have access to appropriate palliative care services. People with dementia often receive suboptimal end of life care. Cognitive and communication problems make it more difficult to provide appropriate palliative care which should nevertheless be readily available. The spiritual dimension is integral to high quality end of life care. Depression (which is potentially treatable) should always be considered in older people seeking euthanasia. The psychiatrist, whose patients may be severely incapacitated and lack competence to reach an informed decision, should be particularly careful of actions that could lead to the death of those who cannot protect themselves because of their disability (World Psychiatric Association, 2005). Advance directives (or previous clearly expressed wishes) regarding the withholding of treatment should however be respected. Attitudes and legislation regarding assisted suicide/euthanasia vary widely and practice must adhere to existing laws and ethical codes of conduct. It should be borne in mind that (in contrast with public preconceptions) quality of life may be good despite progressive deterioration in cognitive function.

### PARTICIPATION IN RESEARCH

The evidence-base for many psychiatric treatments is lacking in older people and more research is needed. Such research needs to involve older people with mental illness. Older people with mental illness should have the right (and be given the opportunity) to participate in research, even if they lack capacity. Capacity may be enhanced by providing information in an easily understandable form. Safeguards are however needed to ensure that participants who lack the capacity to give informed consent are protected. Health-related substitute decision makers should have the authority to give proxy informed consent unless there is specific legislation specifying otherwise. People preparing advanced decisions/directives should be encouraged to include a statement addressing their wishes concerning participation in research. Mental health professionals involved in genetic research or counselling should bear in mind that the genetic information has implications beyond the individual participant and can have negative and disruptive effects on families and communities (World Psychiatric Association, 2005).

## CONCLUSION

Consideration of ethical issues is an essential component of good clinical practice. Ethical issues are often complex, sometimes conflicting. This document will help clinicians understand the principles and synthesise the ethical nuances they face every time they meet patients.

## CONFLICT OF INTEREST

The Consensus Conference received an unrestricted educational grant from Servier Pharmaceuticals, and financial support from the Academic Unit for Psychiatry of Old Age, University of Melbourne.

## APPROVAL FROM HUMAN RESEARCH ETHICS COMMITTEE

Not applicable

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