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Nytt om forskning, utvecklingsarbete och undervisning på äldreområdet i Norden

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Ethical considerations in research on frail older persons

Aging is the process that converts young adults, most of them healthy and in no need of assistance from the health care system, into older adults whose deteriorating physiological fitness leads to progressively increasing risk of illness and death. Gerontology is the science of what is happening in this process of ageing. Inevitably, old and frail individuals that must be considered vulnerable are subjects of gerontological research. This requires special attention, care and wisdom. Organising and carrying out research is also complicated by problems in obtaining informed consent, compliance of treatment and the fact that many patients are lost for follow up. Still we are doing it – and it is important!

In this difficult field of research we need, even more than other researchers, tools to help us. This is why Jon Snædal, in this issue of GeroNord, provides us with a reminder about the Helsinki Declaration. The declaration is well known to us, but perhaps it is time to really look into it.

Few weeks ago, ethical consideration in research of frail older patients was the subject of discussion in a seminar for PhD-candidates in geriatrics and old age psychiatry in Norway. Professor Knut Engedal pointed out three important issues; 1) type and quality of research, 2) benefit versus harm, and 3) capacity to receive information and give consent. Often the discussion about ethics in research on frail older persons is limited to the question of capacity and informed consent. The two other points are as important, and it is perhaps appropriate to encourage both researchers and those who evaluate research projects for financing and necessary approvals to be particularly aware that research on vulnerable elderly people should be on important tasks and of high quality. Have this in mind when you are thinking about new project ideas during your summer vacation!

Summer in the Nordic countries is something special. Don’t forget to enjoy the blooming nature and the long evenings and “charge your batteries”!

Anette Hylen Ranhoff

European Silver Paper on the future of geriatric medicine

In September 2008, under the French Presidency of the European Union and with the support of the Polish Minister of Health, a European Summit on Age-Related Disease was organized in Wroclaw (Poland). At this meeting, European politicians, gerontologists and geriatricians gathered to discuss a common approach to future challenges related with age-related disease. Politicians and decision makers from the European Union and Ministers of Health and their deputies from many European countries raised the problems and difficulties to tackle with a growing population with a high burden of disease, and asked scientists to write a consensus document with recommendations for future actions and decisions.

Scientists worked in parallel in three different groups: 1) health promotion and preventive actions, 2) basic research in age-related disease, and 3) clinical aspects of disease in older people. After careful and detailed discussion in each group, chairpersons presented the results in a plenary session, and new input from all the participants was received, until each of the statements and recommendations were accepted by a big majority. Areas with no consensus were excluded from the document.

For a better understanding by decision makers, the consensus document was divided in two different columns: one with facts that were considered settled and agreed by most experts (under the heading *We know*), and a second with recommendations related with each fact (*We recommend*).

Immediately after the Summit, the chairpersons sent the document both to the main authors and to a list of experts (see footnote) that had made presentations at the summit and agreed to review and critically comment the final document.

For scientific aspects of the organization of the Summit, several organizations, under the leadership of the EUGMS, were asked both to review the program and to suggest names of speakers and participants. After the Summit, the Boards of these organizations (EUGMS, IAGG-ER, EAGP, ISG, and ISSAM) agreed to consider the document as an official paper, and help with its dissemination. The name *Silver Paper* was used, reminding grey –silver coloured- hair of our older citizens, for an easier reference. It has been sent officially to several bodies of the European Union and to Health Ministers of most European countries; and will be published in other languages in local journals. **Its declared intention is to foster changes in policies that can reduce, in the future, the burden of disease in old age.** The consensus document “The European Silver Paper” can be found on the EUGMS website: www.eugms.org

Karen Andersen- Ranberg

Konferanser

2th European Congress on the Ageing Male. September 3-4, 2009. Budapest, Hungary.

Visit http://www2.kenes.com/aging/Pages/welcome.aspx?ref6=db1.

The Ninth International Conference Social Context of Death, Dying and Disposal DDD9 University of Durham September 9-12, 2009

Visit http://www.dur.ac.uk/cdals/ddd9conference/

The Gerontological Society of America. 62nd Annual Scientific Meeting. November 18–22, 2009 • Atlanta, GA. Visit www.geron.org for abstract submission instructions and information.

The Declaration of Helsinki

The Declaration of Helsinki (DoH) is the best known document of the World Medical Association (WMA) and is a core ethical document concerning research on humans. It was initially adopted in 1964 in Helsinki and has been revised several times since then. It is referred to by legislators, research ethical committees, regulators and by the pharmaceutical industry in the context of research on humans. By revisiting the document and making adjustments according to current, best ethical practice, the DoH has remained a living document with a strong influence on medical research ethics. The last revision was made in October 2008. As geriatric research in the Nordic Countries often involves the participation of living persons it is important for those conducting such research to be familiar with this declaration.

The DoH deals with many central issues of human research. The first basic principle is found in paragraph 11 and reads: “It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects.” The following paragraphs deal with the establishment of a thorough research protocol, the quality of researchers, estimation of benefits and risks and then there are paragraphs concerning research on vulnerable populations. It was decided not to specify what was meant by vulnerable population as that list could be very long and would differ from one culture to another. It is however imperative that the sick elderly must be regarded as a vulnerable study population. The autonomy and privacy of participants is addressed and his rights to information and in connection to that, the use of informed consent. The informed consent is described in some detail and also what to do when the participant is unable to fully understand the content of the research he is asked to participate in.

Demented individuals are not specifically mentioned but the two paragraphs that relate to research on persons with dementia are nr. 27 and 28:
Par. 27: “For a potential research subject who is incompetent, the physician must seek informed consent from the legally authorized representative. These individuals must not be included in a research study that has no likelihood of benefit for them unless it is intended to promote the health of the population represented by the potential subject, the research cannot instead be performed with competent persons, and the research entails only minimal risk and minimal burden.”
Par. 28: “When a potential research subject who is deemed incompetent is able to give assent to decisions about participation in research, the physician must seek that assent in addition to the consent of the legally authorized representative. The potential subject's dissent should be respected.”

It is not explained what is meant with legally authorized representative and that might differ from one country to another. It might even differ between the Nordic Countries according to their legislation on the rights of patients or other relevant legislation and therefore it is not possible to give a more detailed account on the practical implication this might have. On the other hand it is clear that whenever a demented individual has any potential to give his view he should be asked and his will should be respected even if he is deemed incompetent.

The most controversial paragraph in the document deals with the use of placebo. When the latest revision was adopted it was not supported by all Medical Associations because of different views on that single topic. Placebo is only mentioned on one paragraph:
Par. 32 “The benefits, risks, burdens and effectiveness of a new intervention must be tested against those of the best current proven intervention, except in the following circumstances:
The use of placebo, or no treatment, is acceptable in studies where no current proven intervention exists; or
Where for compelling and scientifically sound methodological reasons the use of placebo is necessary to determine the efficacy or safety of an intervention and the patients who receive placebo or no treatment will not be subject to any risk of serious or irreversible harm. Extreme care must be taken to avoid abuse of this option.”
Representatives from countries where the use of placebo has been most criticized saw the second bullet point as a way for researchers to circumvent the ban on placebo when a proven intervention is available. It was therefore decided to start a work on the placebo issue specifically and that work is now ongoing.
Lastly I urge all those conducting research on humans or are planning to do so to be familiar with this document, not only to be on the safe side but because this document contains very good information on how to conduct ethical research.

Dr. Jón Snædal, 2. vice president of the NGF and immediate past president of the WMA

The Declaration of Helsinki: http://www.wma.net/e/policy/pdf/17c.pdf

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Cognitive and olfactory changes in aging

Age is associated with decrease in several cognitive functions whereof some changes may indicate a beginning pathologic process resulting in a state of dementia. The studies included in the thesis demonstrate that deficits in cognitive performance, demonstrated in verbal learning and memory tasks, can be related to the ApoE ε4 allele. A series of studies on olfactory functioning revealed the applicability of the Scandinavian Odor Identification Test (SOIT) in middle aged and older individuals the Norwegian population. It was shown that olfactory dysfunction increases with age and that those changes often remain unnoticed. The ability to identify odors was associated with a varying number of cognitive measures depending on the demands of the task. The findings revealed further that individuals who were unaware of their olfactory dysfunction performed lower on a number of cognitive measures which seems interesting in the context of other studies showing that unawareness of dysfunction may appear in early dementia. In conclusion, this thesis strengthens the generality of previous findings demonstrating an association between ApoE ε4 and impaired performance on verbal learning and memory tasks. The findings indicate further that odor identification performance is associated with a number of cognitive measures, predominantly episodic memory functioning. Odor identification tasks may provide valuable information in the examination of elderly individuals at risk for pathological decline.

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Technology and good dementia care:

A study of technology and ethics in everyday care practice

This thesis is about dementia care; about what dementia care is, and, in particular, about what role technology has in care. The starting-point of the investigation is the implementation and use of smart home technology, such as alarms- and monitoring devices in dementia care in Norway. This use of technology is controversial and is linked to legal/ethical discussions of surveillance and coercion. The thesis examines this phenomenon by analyzing the assumptions and positions on technology that current policy on technology and care is based upon, and comparing these with empirical studies of dementia care practices. Drawing on theoretical resources from the academic field Science and Technology Studies (STS) the leading questions are: what does it imply that policy has been framed as a legal issue, and how may concepts used in an empirical approach and a view from within (practices) supplement current policy? Following on from this the thesis addresses normative questions and issues; such as what is good care, and how is good care achieved. The emphasis is on demonstrating that care can be understood as an ongoing and creative process of trying out different care-arrangements. Further, the thesis shows how technology and materiality are a part of – and participates in – this process of constituting care. The argument is that care is constituted through the *concrete* relations between humans and technology. Good care is hence understood as situated, as something that needs to be determined in the actual context of care. Whether the use of smart home alarms contributes to surveillance or coercion is thus an empirical question.

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Health-related quality of life among nursing home residents

Aims: The main aims of the study were to explore health-related quality of life (HRQOL) among nursing home (NH) residents and to compare the HRQOL variables between NH residents and the general population of Norway. Further, the study examined whether psychosocial factors such as sense of coherence (SOC) and social support were related to HRQOL and whether SOC modifies the relationship between social support and HRQOL.

Method: The main sample comprised 227 mentally intact residents from 30 NH in the Municipality of Bergen. A general population sample (*n* = 1137) was used as a comparison group for HRQOL. A cross-sectional design and a cross-sectional comparative design were used. For the NH sample, the data were obtained through face-to-face interviews, whereas the questionnaires in the population survey were self-administered. The SF-36 Health Survey (SF-36) was used to assess the NH residents' HRQOL, and the Sense of Coherence Scale (SOC-13) was used to measure SOC. The revised Social Provisions Scale (SPS) was used to measure social support. In addition, sociodemographic and medical variables were registered.

Results: Residents scored highest on bodily pain, social functioning and role–emotional functioning and lowest on physical functioning. Those with any hobby or interest reported significantly better vitality and mental health than those with none. The sample groups differed significantly for all SF-36 subscales except social functioning. NH residents scored significantly better on bodily pain (less pain), role–physical and role–emotional than the general population. Age and educational level influenced the scores on all subscales. The sum scores of SOC and all SF-36 subscales were positively correlated. The strongest correlation was between SOC and mental health score ($r = 0.62$) and the weakest one between SOC and bodily pain ($r = 0.28$). Attachment significantly affected the mental health subscale, opportunity for nurturance significantly affected the social functioning subscale and reassurance of worth significantly affected vitality after adjustment for age group, sex, marital status, educational level and comorbidity. Including SOC in the analysis reduced the still-significant effect of nurturance on social functioning. Similarly, the effect of reassurance of worth on vitality was also reduced but still significant. However, the relationship between attachment and mental health disappeared. No interactions were found ($P = 0.34$–0.69), and SOC-13 score significantly affected all SF-36 subscales.

Conclusion: NH residents reported highly limited physical functioning and slightly limited social functioning. Further, NH residents had lower HRQOL than the general population except for bodily pain and role limitation, both physical and emotional. The relationship between SOC and SF-36 subdimensions did not change after adjustment for demographic variables and comorbidity. The relationships between NH residents and significant others appear to be an important component of mental health, and the opportunity to provide nurturance for others appears to influence social functioning. Further, the findings show that a sense of competence and self-esteem appear to be important for vitality. Finally, SOC did not modify the effect of social support on HRQOL; social support is a vital resource for better HRQOL. Knowledge from this study is important for NH staff in their daily practice, and more attention may need to be paid to the HRQOL of NH residents and factors that may improve HRQOL.

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”A quantitative psychological study of Posttraumatic Stress Disorder in elderly bereaved people and the impact of personality on the grief reaction.

Loss of a spouse in old age is something many people will experience during their lifetime. At the same time the loss of the spouse is described by many elderly bereaved as the most distressing life event. As the loss of a spouse in old age is a relatively common event, elderly couples will to some extent be able to anticipate the loss, which has lead to the assumption that this type of loss cannot be considered to a traumatic event, and thus cannot lead to Posttraumatic Stress Disorder (PTSD). However, according to the DSM-IV definition of the A1 criterion of PTSD the death of a loved one qualifies as a possible traumatic stressor.

The main aim of this thesis was to explore loss of a spouse in old age as a potentially traumatic experience, to identify frequencies of PTSD longitudinally following the loss, and to investigate whether specific factors could predict who was in high risk of developing PTSD as a consequence of the loss.
Secondary aims were to investigate 1) the relationship between PTSD and adult attachment styles, 2) the effects of different diagnostic criteria of PTSD on PTSD-prevalence rates, 3) the factor structures of PTSD, Complicated Grief and combinations of the two syndromes, and 4) the effect of different recruitment styles on response rates in a clinical control group.
The thesis consists of a general introduction to the theory behind the project and a presentation and discussions of the results from the Ph.D. project followed by a series of 7 research papers (see paper summaries in chapter 8).
The main project consisted of contacting all elderly bereaved who lived in Aarhus County and who lost their spouse in 2006 approximately two months after the loss, and inviting them to participate in a questionnaire study. Half of the participants were offered a personal visit. For the other half the questionnaire was enclosed with the information letter. All participants were followed up with postal questionnaires at 6, 13, and 18 months post loss. A control group of married elderly people from the same geographical area were also included in the study. Approximately four times as many elderly bereaved (16%) as in the control group (4%) fulfilled the diagnostic criteria for PTSD. The frequency of PTSD in the elderly bereaved maintained the same level throughout the four points of measurement. Early posttraumatic distress was the strongest predictor for PTSD 18 months post loss. It can be concluded, that for some elderly bereaved the loss of a spouse in old age is a traumatic experience, and that early posttraumatic distress may be important to include in early screening when planning preventive interventions. This part of the project is presented in detail in the first three papers of this thesis.
The relationship between PTSD and adult attachment styles (paper 7) and the effects of different diagnostic criteria of PTSD on prevalence rates (paper 4) were investigated in a population of Danish students while the effect of different recruitment styles on response rates in recruitment of a clinical control group (paper 5) and the factor structures of PTSD, Complicated Grief and combinations of the two constructs (paper 6) were investigated with participants from the control group of the main study. In the first study significant differences in PTSD prevalence according to the overall diagnostic criteria applied were identified, as was a continuous fall in PTSD prevalence as more of the specific DSM IV criteria were applied. Results from the second study indicated that secure attachment style was significantly associated with a low level of PTSD while dismissive and fearful coping styles were significantly associated with a high level of PTSD. In the third study significant differences in response rates according to recruitment style were identified, and based on these results small monetary incentives can be strongly recommended to increase response rates when recruiting control groups for clinical studies. In the final study we found that a five factor model of CG and PTSD combined where all factors were allowed to correlate was the best fitting combined model, leading to the conclusion, that the conceptual overlap between the dimensions of CG and PTSD is extensive.

Professor of Geriatrics in Iceland

In June this year the Medical Faculty in University of Iceland decided to promote Dr. Palmi V. Jonsson to a full professor of Geriatrics. This is the first academic post in geriatrics of this degree in Iceland but teaching in geriatrics has however been strong for almost two decades. Due to the quality of teaching, which always has been rated high amongst students, interest in geriatrics has been growing among young doctors. Hence, the number of geritricians in Iceland is proportionally the highest of the Nordic Countries.

Palmi V. Jonsson is well known amongst academic geriatricians in Nordic countries as he has been active in the Professor meetings for several years, collaborated in publication on the behalf of the group and organized courses. He graduated from the Medical Faculty at University of Iceland in 1979. After training years in Iceland he was resident in Internal Medicine at University of Connecticut and subsequently a Fellow in Geriatrics at Harvard University 1986-1989 and an instructor of medicine at Harvard 1988-1989. After returning to Iceland he worked as a specialist in geriatrics at Reykjavik Hospital which later merged into the Landspitali University Hospital. From 1994 he has served as Chief of the Geriatrics. In 1994 he was appointed Associate Professor of Geriatrics and has since been responsible for teaching of geriatrics in Iceland.

His initial research interest was in blood pressure regulation and falls. He wrote a chapter of dizziness and syncope in two editions of the textbook Principles of Geriatric Medicine and Gerontology. Later he became involved in the InterRai work and serves on the Board as well as having been active in the NordRai group. He is a c0-principle investigator (responsible for the brain part) of AGES study, the longitudinal Reykjavik Heart Study in collaboration with NIA in the US.

He has published over 100 articles in per reviewed journals and chapters in text books. His appointment as Professor of Geriatrics is well deserved.

Jon Snædal

20 NKG – call for symposia

The 20th Congress in gerontology will be held in Reykjavik, Iceland 31 May – 2. June 2010. The program is unfolding but we need of course more input from the scientific communities in the Nordic countries.
The congress will follow traditional lines with plenary sessions, state of the art lectures, organized symposia, oral sessions and poster sessions.
We hereby ask all those interested in organizing symposia to send in their applications to the scientific committee: olafs@landspitali.is. The dead line is 1. Nov. 2009. Each session is 90 minutes and the organizer can choose to some extent the number of presenters but 4-6 is the usual number. Each presenter must submit an abstract for evaluation in the same manner as others as will be outlined on the web site of the congress: www.congress.is/20nkg

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