In the past two decades *Nursing Ethics* has published a total of 25 articles with a primary focus on the ethical care of a person with dementia. In addition to full articles there have been references to individuals with cognitive deficits in editorials, short comments and in book reviews in the journal.

A common theme in many of the articles dealing with the ethical care of a person with dementia is the nursing personnel’s lack of respect for individuals who have cognitive deficits. These persons are not treated as human beings with individual needs but rather as a stereotypical group who are often subjected to various forms of coercion, restraints and restrictions. In one sense this lack of respect is a sign of a more generalised ageism: if a person is older, care staff assume that he or she must have a cognitive deficit. The authors of the articles are concerned about giving a voice to the voiceless in all areas of their care, particularly in arguing for their participation in research into dementia care in order to improve it to meet the needs of individuals and families.

The two most recent articles on dementia care are part of a larger Norwegian interview study titled *Hospice Values in Care for Persons with Dementia*. Because of their ongoing commitment to the improvement of care for persons with dementia, the four authors, Egede-Nissen, Jakobsen, Sellevold and Sorlie use more comprehensive approaches in their investigations into the ethical issues confronting those who care for individuals with dementia. In the first of these [1] they analyse both subjective and objective concepts of time both from the perspective of the health care providers and the persons with dementia. Theirs is an original, more thoughtful and sophisticated way of dealing with the prevalent nursing problem commonly just identified as “lack of time”.

The authors emphasize the importance of subjective time for both nurses and those they care for, and for the relationship of trust that needs to develop between them so that the quality of care and interactions is enhanced and can flourish. In their most apt terms, both parties need to be liberated from the “metric straight jacket”. In Ann Gallagher’s words in a recent editorial, *slow ethics* are conducive to richer relationships.

The same Norwegian authors continue the theme of the relationship between nursing personnel and persons with dementia in their second article. They regard it as a key factor in the exercise of quality care; they highlight the importance of reciprocity in communication. [2] Hermeneutic and phenomenological philosophers, first amongst them Paul Ricoeur with his seminal work *Time and Narrative*, provide the conceptual framework to these articles, with the addition of the works of Gadamer, Merleau-Ponty and Levinas in the second.

An earlier article [12] by the same Norwegian research team raised concerns about the use of restraints and the limitations of autonomy and freedom. The team highlight lack of time as an obstacle to the provision of individualized care.
Care staff act in unethical ways that may be attributed to their lack of time and to their lack of respect for individuals with dementia; one prevalent example of this is the continuing use of physical restraints. Authors from Sweden and Israel focus on this ethical issue and identify the nurses’ lack of education as a further factor in this practice. The authors report that it is still the case that nurses use restraints without consent in order, as they perceive it, to prevent physical harm such as falls. As many research articles into the issue show, however, the harms of restraints outweigh their benefits. Nurses still fail to do proper risk assessments because they lack education and are unaware of patient-centred approaches to caring for older people. As Lejman, Westernbotn, Poder and Wadensten argue [3], the use of physical restraints can conflict with national and international legislation as the freedom and movement of an individual is restricted.

Weiner, Tabak and Bergman had taken up the issue of Israeli national legislation and the use of physical restraints on individuals with dementia [7] a decade earlier than the authors above. They do not discuss the lack of consent but focus on human rights; can the risks to human life justify the overriding of human rights such as autonomy?

Israeli authors Ehrenfeld, Bronner, Tabak, Alpert and Bergman have written the only paper on sexuality among institutionalised elderly patients with dementia [17]. They conclude that nurses need education on the sexual needs of institutionalised elderly patients with dementia.

Yamamoto and Aso highlight the Japanese situation where physically restraining older people is prohibited by law, but where they are still used in many general hospitals in acute care [16]. The authors outline three coping mechanisms used by nurses when faced with the dilemma of physically restraining older people, positive and negative cognitions and actions as well as inaction.

The person’s autonomy and capacity to choose is the topic of the article by Wilmot, Legg and Barratt on ethical issues in the feeding of patients suffering from dementia [5]. Can a person with dementia refuse food, and thus exercise his or her autonomy? Or should the care staff deem such persons incapable of making such decisions and coerce them to eat in order to meet their nutritional needs?

In the first volume of the journal Watson already raised the ethical issue of feeding people with dementia, particularly when feeding should be stopped at the end stages of the illness [21]. He refers to an article by Nordberg and Hirshfield, based on research in various countries. A version of this article by Nordberg, Hirshfield et. al. on the international perspective on this ethical issue was published in the same volume [22]. In Scandinavian countries feeding was ceased earlier than in Israel or in China. The authors argue for the application of the four “universal” principles of autonomy, beneficence, non-maleficence and justice in order to make sound clinical decisions. At the same time they show how they conflict with Confucian ethics based on harmony and relationships, not individualism. The applicability of Western “universal” principles cannot be advocated in other cultural settings; they have their limitations even in ordinary ethical situations when many individuals with different values are involved.

Tannsjo argues that in some instances there is room for the legitimate use of modest coercion but he argues against meddlesome coercion at all times [20]. As a medical professional Tannsjo recognises that in order to ascertain what demented patients really want, nurses need “much compassion, skill and even courage”. He argues for the role of caregivers as decision makers, and against proxy decision making.

As can be seen from the review of a small number of articles so far, the authors agree that the provision ethical care of a person with dementia amounts to more than meeting the basic physical needs of the individual. Even when his or her cognitive capacities may fluctuate and may be gradually impaired, the care staff should still ensure that there are opportunities for the person to flourish
through interactions with others. Kalis, Schermer and van Delden argue in their qualitative study that
when ideals about what a good life for nursing home residents with dementia amounts to, the
subjective values of the individual should determine this, not the often conflicting ideals of the care
givers [4]. In other words, the voices of the nursing home residents should be heard so that they can
play an active role in shaping a good life for themselves.

Bolmsjö, Edberg and Sandman refer to the study of Kalis, Schermer in their investigation into the
everyday ethical problems in dementia care [6]. They agree that the aim of the care of a person with
dementia should be the good life. Sandman has developed a teleological model that can be used in
the identification of a situation as well as the assessment and implementation of various alternative
ways of acting in the situation.

Many of the authors referred to so far appeal to ethical principles derived from moral philosophy.
Wilmot, Legg and Barratt refer to Kant’s principle of autonomy and Mill’s ethical principle of utility
[5] and how these may be balanced against each other in the cases of particular individual residents.
They further cite the work of Gallagher who argues for the avoidance of benevolent paternalism and
for respecting autonomy. Sandman’s teleological model of care is derived from virtue ethics; he and
his co-authors refer to the works of contemporary bioethicists, most notably Daniel Callahan, Soren
Holm and Helga Kuhse as well as to the Beauchamp and Childress’ seminal text Principles of
Biomedical Ethics.

Kuhse is best known for her critique of the ethics of care as an inadequate ethical theory for several
reasons that she argues for most stridently. Amongst the articles on the care of a person with
dementia, however, there is an excellent article that is unique in its ethics of care approach. Barnes
and Brannelly in their article titled “Achieving care and social justice for people with dementia” make
references to the work of Joan Tronto, Moral Boundaries: A Political Argument for An Ethic of Care
[8]. The authors recognise that care has a political dimension; in a particularly illuminating section of
the article, “Care in practice” they highlight how well Tronto’s four moral principles of attentiveness,
responsibility, competence and responsiveness can be applied to the care of a person with dementia
and also to the problems faced by their carers.

Heggstad, Nortweldt and Slettebo argue for the inclusion of persons with dementia as research
subjects, particularly in research in which persons they could express their feelings and experiences
[9]. They argue for the importance of moral sensitivity on the part of the researchers who must be
able to appreciate the experiences of the person from their individual perspective.

Pesonen, Remes and Isola also deal with the role and relationship of the researcher to the subjects of
their research [13]. They aim to provide “a theoretical understanding of what it means to be living
with dementia”.

In contrast to the two research studies from the Nordic countries, Brannelly, the second author of
the above article on achieving social justice for people with dementia [8], reports that a UK health
research committee rejected her original research design which included interviews with people with
dementia in favour of observation [14]. She argues that people with dementia are treated as if they
were socially dead; they are no longer included in society as active citizens but are disregarded.

Hellstrom, Nolan, Nordenfelt, and Lundh argue that personal interviews of people with dementia
have more advantages than disadvantages [15]. The authors put forward several good arguments for
the inclusion of people with dementia as active research subjects: “The imperative to actively include
people with dementia is strong, and their exclusion can be ethically justified only if it seriously
contravenes ethical principles”.
There is one article amongst the articles on research on people with dementia that stands out from the rest because the authors are concerned with people in the middle and late stages of dementia [18]. The Canadian authors Slaughter, Cole, Jennings and Reimer argue for conducting research with people who have dementia: “Assuming people with dementia are unable to participate in research reinforces negative stereotypes of incapacity, and denies them the opportunity to make a meaningful contribution to research and share its benefits”.

Long and Slevin suggest that one way for nursing students to develop moral sensitivity is to act in role plays [10]. Through these they can identify many components of interaction between a person with dementia and those caring for him or her. Examples of these are use of power and restriction, truth telling, family stress, interpersonal conflict, ageism and sexism, empathy and humanism. The authors cite the works of nursing theorists Benner and Watson as well as hermeneutic and phenomenologist philosophers Husserl and Merleau-Ponty. Most notably they quote DH Lawrence on how difficult it is to put into words how you deeply care for someone else. In other words, good literature often has as much or more to say about ethics than philosophy; a good, engaging story can promote moral sensitivity better than anything else.

Even if an author as distinguished as Lawrence may have admitted to an inability to find the words on some rare occasion, the use of the right words does matter in our communications with others and in how we describe our interactions with them. Norbergh, Helin, Dahl, Hellzen and Asplund illustrate the effect of words on nurses attitudes towards people with dementia by adopting a semantic approach [11]. They highlight the close connection between aesthetic and ethical adjectives. If we describe an older person as smelly, our language reflects our moral attitudes.

The moral attitudes of health professionals are displayed by their attitudes to lying to people with dementia. Tuckett concludes that these contain much confusion and contrariness [19]. He argues that much of this can be avoided by communicative interventions based on a theory combining aspects of deontology and utilitarianism with the added dimension of virtue ethics.

Treating people with dementia as individuals is one of the most important ethical themes in each article discussed so far. The individual is at the centre of discussions in the final three. Echoing Brannelly [14], Butts and Rich argue that persons with dementia are the new social outcasts [23]; in their contribution they adopt the perspective of the person with Alzheimer’s who experiences emotional trauma and fear. They add further that the whole family is surrounded by “the umbrella of gloom”.

Randers and Mattiasson have contributed two sensitive articles on the loss of individuality experienced by persons who are admitted to aged care [24,25]. Even those who are cognitively intact are treated as it their views and experiences no longer matter.

As many of the research projects cited are ongoing, the researchers are to be commended on their work on behalf of the voiceless persons with dementia. The many empathetic narratives included and carefully analysed by means of appropriate classical and contemporary ethical theories demonstrate the need to treat each person with dementia as an individual with needs and fears but also with hopes and wishes for the future. As nurses we are asked by the researchers and their active subjects to move from social exclusion to social inclusion of members of our communities. We are all richer for giving of our time to each other; instead of working within a metric straitjacket we should dream of growing wings to fly.
References


5. S Wilmot, L Legg and J Barratt, *Ethical issues in the feeding of patients suffering from dementia*: a focus group study of hospital staff responses to conflicting principles, Volume 9 Number 6, 2002: 599-611.


9. Anne Kari T Heggestad, Per Nortweldt, and Ashild Slettebo, “*The importance of moral sensitivity when including persons with dementia in qualitative research*”, Volume 20, Number 1, 2013: 30-40.


24. I Randers, TH Olson and A-C Mattiasson, *Confirming older adult patients’ views of who they are and would like to be*, Volume 9, Number 4, 2002: 416-431.