The full spectrum of ethical issues in dementia care: systematic qualitative review

Daniel Strech, Marcel Mertz, Hannes Knüppel, Gerald Neitzke and Martina Schmidhuber

Background
Integrating ethical issues in dementia-specific training material, clinical guidelines and national strategy plans requires an unbiased awareness of all the relevant ethical issues.

Aims
To determine systematically and transparently the full spectrum of ethical issues in clinical dementia care.

Method
We conducted a systematic review in Medline (restricted to English and German literature published between 2000 and 2011) and Google books (with no restrictions). We applied qualitative text analysis and normative analysis to categorise the spectrum of ethical issues in clinical dementia care.

Results
The literature review retrieved 92 references that together mentioned a spectrum of 56 ethical issues in clinical dementia care. The spectrum was structured into seven major categories that consist of first- and second-order categories for ethical issues.

Conclusions
The systematically derived spectrum of ethical issues in clinical dementia care presented in this paper can be used as training material for healthcare professionals, students and the public for raising awareness and understanding of the complexity of ethical issues in dementia care. It can also be used to identify ethical issues that should be addressed in dementia-specific training programmes, national strategy plans and clinical practice guidelines. Further research should evaluate whether this new genre of systematic reviews can be applied to the identification of ethical issues in other cognitive and somatic diseases. Also, the practical challenges in addressing ethical issues in training material, guidelines and policies need to be evaluated.

Declaration of interest
None.

Clinical practice guidelines, national strategy plans (such as the French Alzheimer plan), the World Alzheimer Reports, and many scientific and non-scientific publications all stress the existence of various ethical issues in dementia care and the importance of awareness and capacity building in this area. A core challenge for the adequate development of reports, guidelines and training programmes that address ethical issues in dementia care is an unbiased and comprehensive account of all (discussed/reported) ethical issues at stake. Such an unbiased and comprehensive set of ethical issues (a full spectrum of ethical issues) in dementia care can be based on a systematic literature review. This review serves several purposes. First, it raises awareness of the variety of ethical issues and the complexity of ethical conduct in dementia care. Second, together with a comprehensive list of the underlying publications, it can be used to build the basis for the systematic development of information and training materials for health professionals, relatives, patients or society as a whole. Finally, it can be used as the basis for a rational and fair selection of all those ethical issues that should be addressed (with more or less priority) in health policy decision-making and national or local dementia strategies, position papers or clinical practice guidelines.

There are several recent books, reports and review papers intended to highlight (implicitly or explicitly) the range of ethical issues in dementia care. To date, the British Nuffield Council on Bioethics report Dementia: Ethical Issues is probably the most extensive. Its development involved a working group of 14 experts (mostly from the UK), public consultations, fact-finding meetings and peer review. However, the report, as well as most other existing overviews, could be classified as a narrative (non-systematic) review that did not employ explicit measures to prevent bias and to guarantee comprehensiveness in identifying and presenting relevant literature. Also, the Nuffield Council report is, understandably, oriented specially to the situation in the UK. Furthermore, because of their narrative approach, the mentioned reviews are not structured in a way that clearly illustrates the full spectrum of ethical issues in dementia care. To our knowledge there is only one review of all ethical issues in dementia that employed a systematic review methodology. This review focused on the older literature published between 1980 and 2000 and presented ethical issues in only one small-scale table listing 20 broad categories (for example advance directives, decision-making or feeding issues) and some examples of subcategories (such as living wills, euthanasia, genetics). This review did not include any further explanation of ethical issues in dementia care, nor link the set of ethical issues to the retrieved references. Another systematic review focused more specifically on empirical literature studying ethical issues in dementia from the perspective of non-professional carers.

The purpose of our review was to determine the full spectrum of ethical issues in clinical dementia care based on a systematic review of the recent literature published between 2001 and 2011 (including journal articles, reports and books). We define a ‘full spectrum of disease-specific ethical issues (DSEIs)’ as a structured, qualitative account of ethical issues in the context of a specific disease (such as dementia), divided into broad categories and narrow subcategories that are based on text examples from the original literature that was included in the review. The purpose of our review is purely descriptive (‘empirical’ in its literal meaning). A description of the full spectrum of DSEIs prepares the ground for the planning and development of clinical guidelines, national and local dementia strategies and curricula for teaching and capacity-building activities. The aim of our review, therefore, was not to make judgements on the practical relevance or value of specific ethical issues. Moreover, this review does not present any normative recommendations on how to deal with every single ethical issue detected. In the discussion section, however, we highlight core methodological steps that should be
or against physical restraints on account of inappropriate patient harms and the respect of patient autonomy in decision-making for (specified) ethical principles (for example, balancing the benefits, of one or more (specified) ethical principles (for example: a DSEI might arise (a) because of the inadequate consideration against one another. With respect to the principlism approach, principles have to be specified and – if they conflict – balanced guidance in concrete cases. Thus, when being applied, the case, with an equal or greater obligation. Moreover, they provide norms that must be followed unless they conflict, in a particular case, with an equal or greater obligation. Moreover, they provide only general ethical orientations that require further detail to give guidance in concrete cases. Thus, when being applied, the principles have to be specified and – if they conflict – balanced against one another. With respect to the principlism approach, a DSEI might arise (a) because of the inadequate consideration of one or more (specified) ethical principles (for example: insufficient consideration of patient preferences in dementia care decisions) or (b) because of conflicts between two or more (specified) ethical principles (for example, balancing the benefits, harms and the respect of patient autonomy in decision-making for or against physical restraints on account of inappropriate patient behaviour).

We included a publication only if: (a) it described a DSEI in clinical dementia care, and (b) the DSEI can be dealt with by individual caregivers or care institutions and does not depend on preceding health policy or political decision-making (for example campaigns for reducing the stigma of dementia, political decisions about the limitations of voting by people with dementia), and (c) it does not relate only to ethical issues in research on dementia (research ethics), and (d) the publication was a peer-reviewed article, a scientific book (for example textbooks or monographs) or a national-level report.

Extraction and categorisation of DSEIs

Our aim was to develop a qualitative framework of narrow and broad categories of DSEIs (the full spectrum of DSEIs) that best accommodated the DSEI mentioned in the included publications. We identified and compared paragraphs that mentioned DSEIs across papers. We matched discussion of DSEIs from one paper with DSEIs from another. We then built first-order (broad) and second-order (narrow) categories for DSEIs that captured similar DSEIs mentioned in different papers.

Paragaphs from the retrieved literature were extracted that described situations that explicitly or implicitly relate to our definition of DSEI. Extraction and categorising of DSEIs unavoidably involves interpretative tasks (for example which text passages deal with a DSEI? What is the appropriate broad and narrow category for the DSEI?). To uphold the validity of coding as well as intercoder reliability we employed the following procedure. Three authors (D.S., M.M. and M.S.) identified and initially categorised DSEIs independently in a subsample of five publications that all could be classified as narrative reviews.1-6,12 The authors discussed whether paragraphs mentioned a DSEI and how they should be categorised. The remaining 87 publications were grouped in three clusters of 47, 20 and 20 publications. All publications that at initial inspection appeared to be more detailed and comprehensive were purposively put together in the first cluster of 47 publications. One author (M.S.), with a PhD in philosophy, then extracted and categorised DSEIs from this first cluster. The result was a first version of the DSEI spectrum. The second and third clusters were then used to check theoretical saturation of the DSEI spectrum. Theoretical saturation implies that no new categories can be generated.13 The other authors (D.S., M.M., G.N. and H.K.) with professional backgrounds in clinical psychiatry, clinical ethics consultation, philosophy and health services research checked the extraction and categorisation of DSEI in a random sample of 18 publications. Coding problems were resolved by frequent meetings and discussions with all authors. Because the aim of our review was not to assess how often a certain DSEI was mentioned in the literature we only extracted two paragraphs with similar content for each DSEI. We extracted more than two paragraphs per DSEI only in those cases where the content allowed further specification of a certain DSEI.

Results

Our literature search retrieved 559 references of which 92 were finally included in the review (Fig. 1). More than half (47, 51%) were published between January 2008 and February 2011. Two-thirds were peer-reviewed journal articles (62, 67%) published in 42 different journals including all relevant disciplines (Table 1). Other publication sources were for example book chapters, monographs or reports. Most journal articles and all but one book were written in English (78, 85%).

The 92 publications together included a spectrum of 56 DSEIs that were grouped under seven major categories: diagnosis and indication; patient decision-making competence; disclosure and patient information; decision-making and informed consent; social and context-related aspects; professional conduct and evaluation; and specific care situations (see Appendix). For each major category, DSEIs were further specified in first- and second-order DSEI categories (Appendix). For example, the major category 'Diagnosis and medical indication' consists of 12 second-order DSEIs grouped under 4 first-order DSEIs. An example of a first-order DSEI is 'Adequate point of making a diagnosis'. This DSEI consists of three second-order DSEIs, of which one is 'Risk of disadvosing signs of illness and disregarding advance planning'. A text example (among others) that built the basis for this DSEI is the following: 'But there is also the opposite risk that out of a laudable wish to preserve a person’s freedom and to avoid giving false label to an existential problem, signs of illness are missed and the ill old person is denied necessary and effective treatment.’ We found text passages in other references that allowed further specification of this second-order DSEI. We cite these references in the Appendix, but for didactic and readability purposes we did not further specify third- and fourth-order DSEIs in this paper. Our analysis received theoretical saturation for the first- and second-order DSEI categories after analysing the third cluster of retrieved references (see Method). Online Table DS1 presents one or two text examples for each of the 56 DSEIs. We
therefore have not repeated the presentation of DSEI categories and the underlying text examples in the results section.

The first six main categories involve DSEIs that deal with specific steps in the circular processes of medical decision-making (diagnosis, patient information, treatment/care decisions, evaluation of decisions, etc.) that are characteristic of the management of all diseases but are considered with respect only to dementia in this paper. The seventh major category involves DSEIs that deal with specific situations in the management of dementia that in principle involve all steps of the decision-making process (for example dealing with tube feeding, restraints or suicidality).

Discussion

Dementia care in all its interactions and care situations is deeply intertwined with ethical issues. Dealing with ethical issues in a systematic and transparent manner requires, first of all, an unbiased awareness of the spectrum and complexity of DSEIs. Second, it seems important for didactic and pragmatic purposes to fit this spectrum of DSEIs to everyday care situations and to the stepwise processes of medical decision-making rather than to more abstract philosophical categories or ethical principles.

In this paper we presented the full spectrum of DSEIs in dementia care as they are described in the available scientific literature (including medical and nursing journals, organised public consultations and surveys). Our review covers all DSEIs for dementia care that were presented in the already mentioned systematic review of the older literature published between 1980 and 2000.7 In addition, our review revealed further DSEIs, further specified DSEIs and directly linked the DSEIs to the relevant references. The findings of this comprehensive and detailed review can raise the awareness that general ethical principles such as ‘respect of patient autonomy’ or ‘beneficence’ obviously need specification (see Appendix) to inform medical decision-making in all its different steps (for example information about the patient, assessing patient decision-making competence, evaluating former decisions and current practice).

Categorisation of DSEIs

This review is the first one that demonstrates what the categorisation and reporting of DSEIs can look like. Further evaluation is needed.
to assess the advantages and disadvantages of this structured and detailed reporting on DSEIs, in comparison with other more general and abstract types of reporting or narrative book-length descriptions. However, the detailed categorisation of DSEIs as the main finding of this review highlights a core challenge in applying systematic review methodology to the field of bioethics: the critical appraisal of systematic reviews of ethics literature should not only address the quality of the literature search but also, with equal importance, the validity and usefulness of the synthesis of findings. Thus, in this review, the full spectrum of DSEIs is presented in first- and second-order categories.

This DSEI spectrum can serve various purposes. It can be used as training material for healthcare professionals, students, and the public, to raise awareness and improve understanding of the complexity of ethical issues in dementia care. It can also be used for the systematic and transparent identification of ethical issues that should be addressed in dementia-specific training programmes, national strategy plans and clinical practice guidelines.

We recommend employing the methods applied in this review for the systematic identification of DSEIs in other cognitive and somatic diseases. Although different first- and second-order categories are to be expected for ethical issues in other diseases we assume that the overarching structure of our DSEI spectrum is applicable to all diseases, namely six major categories that deal with the stepwise processes of medical decision-making and one additional major category dealing with specific care situations. Whereas the literature on DSEIs in dementia care was extensive, and therefore allowed theoretical saturation of the respective DSEI spectrum, systematic reviews of DSEIs in other diseases might retrieve fewer references that address DSEIs. To reach theoretical saturation of the respective DSEI spectrum in these cases the systematic literature review might need to be complemented by expert input on DSEIs or surveys of healthcare professionals, patients and relatives. Further research is needed on how these complementary DSEI sources can be integrated in an equally systematic and transparent manner.

**Limitations**

One limitation of this first systematic review of DSEIs might be seen in the fact that we restricted our search to Medline and Google books. It is clear to us that although our review was systematic we did not include ‘all’ the existing literature dealing with ethical issues in dementia care. We restricted our search to the above-mentioned databases for four main reasons: first, and most important, we reached theoretical saturation for the first- and second-order categories of DSEIs after assessing the 92 references retrieved for Medline and Google books. We did not aim to reach theoretical saturation for the third-order categories. Second, former systematic reviews in the field of bioethics demonstrated the broad coverage of ethics literature in Medline and the little additional value of searching medical ethics literature in other databases such as EMBASE, CINAHL or Euroethics.

Third, the characteristics of publications included in this systematic review (Table 1) demonstrate that the 92 references covered journals from all relevant fields. Fourth, the 92 references included several narrative reviews, topic-specific monographs and comprehensive reports such as the Nuffield Council on Bioethics report on dementia. Currently, the field of systematic reviews on ethical issues (or argument-based literature in general) lacks broadly consented standards such as those available for systematic reviews on clinical research, for example Moher et al. Further conceptual and empirical research should address the question on how to modify systematic review methodology for its reasonable application in the field of bioethics.

We stress the fact that a systematic and transparent process in identifying ethical issues does not automatically indicate that further steps in dealing with such a spectrum are systematic, too. Further research is needed to evaluate how health policy decision-makers or guideline-development panels can chose the ‘most important or pressing’ DSEI from the full spectrum in a transparent and participative manner. The purpose of this review was not to quantify how often certain DSEIs have been mentioned in the literature. It is questionable whether such frequency data are helpful. It might, however, be important to know whether a certain DSEI is more or less frequent in ordinary dementia care. However, such frequency data cannot be derived by counting how often a certain DSEI has been mentioned in the literature. Survey research among carers and patients, informed by the findings of this review, would be a better tool for gaining these frequency data. Further challenges in interpreting quantitative characteristics of systematic reviews in bioethics are described elsewhere.

**Ethical decision-making in dementia care**

It should be stated that the process of drafting recommendations on how to deal with individual DSEIs faces several methodological challenges. On the one hand, oversimplification needs to be avoided to guarantee meaningful and helpful content. The Nuffield Council report provides a good example of how some of the complex DSEIs captured in our DSEI spectrum can be addressed by providing a set of criteria that do not indicate a one-size-fits-all solution for ethical challenges but rather guide the process of ethical decision-making in dementia care. A good example is the second-order DSEI ‘Problems concerning understanding and handling of patient autonomy’. The Nuffield Council addresses this DSEI as follows: ‘Wellbeing factors, such as the person’s general level of happiness are also important but again cannot automatically take precedence over the person’s interests in having their autonomy respected’.

In the following, the Nuffield Council suggests factors that should be taken into account when weighing up the conflicting ethical principles in dementia care (well-being vs. respect of autonomy):

1. (i) How important is the issue at stake? (ii) How much distress or pleasure is it causing now? (iii) Have the underlying values or beliefs on which the earlier preferences were based genuinely changed or can they be interpreted in a new light? (iv) Do the apparent changes in preferences or values result from psychosocial factors (such as fear) or directly from the dementia (such as sexually disinhibited behaviour), or are they linked with a genuine pleasure in doing things differently?

Future developments of dementia-care-specific clinical guidelines, information material and national strategy plans can use the findings of this review for the identification and prioritisation of key ethical issues in dementia care. In addition, transparent procedures should be applied for drafting and approving recommendations that guide everyday ethical decision-making in dementia care.

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The spectrum of disease-specific ethical issues (DSEIs) in dementia care

1 Diagnosis and medical indication

Adequate consideration of complexity of diagnosing dementia:
- Risk of making a diagnosis too early or too late because of reasons related to differences in age- or gender-related disease frequencies\(^2,3,25\).
- Risk of making inappropriate diagnoses related to varying definitions of mild cognitive impairment\(^2,3,12,17,26-30\).
- Underestimation of the relatives’ experiences and assessments of the patient with dementia\(^2,30,31\).

Adequate point of making a diagnosis:
- Risk of disavowing signs of illness and disregarding advanced planning\(^2\).
- Respecting psychological burdens in breaking bad news\(^17,30,31,33\).
- Underestimation of the relatives’ experiences and assessments of the person with dementia\(^2,30,31\).

Reasonableness of treatment indications:
- Overestimation of the effects of current pharmaceutical treatment options\(^2,3,34-36\).
- Considering challenges in balancing benefits and harms (side-effects)\(^2,3,34-36\).
- Not considering information from the patient’s relatives\(^2,5,18,37\).

Adequate appreciation of the patient:
- Insufficient consideration of the patient as a person\(^2,3,14,26,30,31,38-40\).
- Insufficient consideration of existing preferences of the patient\(^2,3,14,17,31,34,35,38-40\).
- Problems concerning understanding and handling of patient autonomy\(^2,3,12,40,51,52\).

2 Assessing patient decision-making competence

Ambiguity in understanding competence\(^2,3,14,17,52-57\).

Problematic aspects in patient decision-making competence:
- Inadequate assessment\(^2,3,14,29,57,58\).
- Inadequate consideration of setting or decision content\(^2,3,4,12,59\).
- Disregarding the complexity of assessing authenticity\(^2,3,14,55,60,61\).
- Underestimation of the relatives’ experiences and assessments of the patient\(^2,30\).

3 Information and disclosure

Respecting patient autonomy in the context of disclosure\(^2,3,4,12,35,53,57,59,62\).

Adequate amount and manner of information\(^2,3,4,14,31,33,35,59,62\).

Adequate involvement of relatives\(^2,3,4,33,59\).

Consideration of cultural aspects\(^2,4\).

4 Decision-making and consent

Improvement of patient decision-making competence:
- Risk of inadequate involvement of the patient in the decision-making process\(^5,6,49,53\).
- Risk of insufficient conditions for fostering decision-making capacity\(^2,3,12,63\).
- Risk of disregarding the need of continuous relationship building with the patient as a means to foster patient autonomy\(^2,3,6,53\).
- Risk of setting the time for decision-making processes too short\(^2,3\).
- Risk of weakening patient decision-making competence by infantilisation\(^2\).

Responsible surrogate decision-making:
- Adequate handling of ‘best interest’ and ‘substituted judgements’ decisions\(^2,3,4,6,12,14,17,19,26,30,31,52,53,64-71\).
- Inadequate communication with relatives\(^2,3,6,14,26,37,39,72-78\).
- Inadequate handling of information stemming from relatives\(^2,3,37,53,73,79\).
- Need of advanced planning\(^2,4,6,12,48,75\).
- Risk of disregarding legal clarifications\(^2,3,6\).

Adequate consideration of living wills/advance directives:
- Challenges in interpreting the living will/advance directive\(^2,4,6,41,53,60,66,70,78\).
- Challenges in deciding to follow or not to follow the content of the living will/advance directive\(^2,4,14,34,53,66,67,70\).

5 Social and context-dependent aspects

Caring for relatives\(^2,3,4,12,14,16,30,31,36,77,81-83\).
Caring for clinical personnel and professional carers\(^2,13,77,84-87\).
Assessment of the patient’s potential to do (direct or indirect) harm to others\(^2,4,5,36,88\).
Responsible handling of costs and allocation of limited resources\(^2,3,5,12,27,89\).

6 Care process and process evaluation

Continuing assessment of potential benefits and harms\(^2,3,34-36,90\).
Adequate patient empowerment:
- Patient-oriented setting\(^2,4,12,29,30,39,91\).
Motivation of patients:\(^2,30,31,32,92\).
Self-reflection of carers:
- Attitudes towards patients with dementia\(^2,5,90\).
- Reflection on conflicts of interests and values\(^2,3,5,93,94\).
Continuing education/capacity building of the carers\(^2,4,31,84,95,96\).
Evaluation of abuse and neglect\(^2,4,12\).

7 Special situations for decision-making

Ability to drive\(^4-6,12,88,97\).
Sexual relationships\(^2,12\).
Indication for brain imaging\(^2,98-100\).
Prescription of antibiotics\(^36,68\).
Prescription of antipsychotic drugs\(^2,12\).
Indication for genetic testing\(^2,12\).

Funding

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References


101 Homanen L. Point-counterpoint: is it ethical to give drugs covertly to people with dementia? No: covert medication is paternalistic. West J Med 2001; 174: 229.

102 Lamarni A. Point-counterpoint: is it ethical to give drugs to people with dementia? Yes: it is ethical if it is in their best interests. West J Med 2001; 174: 228.


Table DS1 The spectrum of disease specific ethical issues (DSEIs) in dementia care (complemented by quotations from the original literature)

<table>
<thead>
<tr>
<th>1. Diagnosis and medical indication</th>
<th>Ref.</th>
<th>Quotations for illustration</th>
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<tbody>
<tr>
<td>Adequate consideration of complexity of diagnosing dementia</td>
<td>1, 2</td>
<td>“Not only is psychiatric illness common in old age - so too are physical diseases and social deprivation of all kinds. When a number of such pressures lead to distress in an older person’s life, the diagnostic boundaries of psychiatric illness may be much less clear-cut than in younger people and experienced psychiatrists often set lower threshold for identifying such illness in older people than they do for the young.” [1]</td>
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<tr>
<td>Risk of making inappropriate diagnoses related to varying definitions of MCI (mild cognitive impairment)</td>
<td>1, 3-10</td>
<td>“Early concerns about utility of diagnosing an irreversible, terminal condition such as AD have waned as effective treatments have emerged. […] The diagnosis of MCI is more nuanced, because no effective therapies are available as yet, and, although MCI is a risk factor for the development of AD, its prognosis is not clear.” [10]</td>
</tr>
<tr>
<td>Underestimation of the relatives’ experiences and assessments of the person with dementia</td>
<td>7, 9, 11</td>
<td>“Physicians should be able to explain exactly how patients, for example, are impacted daily by forgetfulness: The statement merely forgetting their name does not provide enough information. The additional information that comes from family members, namely that the patient forgets the names of his children or other pertinent personal information like his age, directs attention to dementia.” [7]</td>
</tr>
<tr>
<td>Adequate point of making a diagnosis</td>
<td>1, 10-12</td>
<td>“But there is also the opposite risk that out of a laudable wish to preserve a person’s freedom and to avoid giving false label to an existential problem, signs of illness are missed and the ill old person is denied necessary and effective treatment.” [1]</td>
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<tr>
<td>Respecting psychological burdens in breaking bad news</td>
<td>7, 8, 11, 13</td>
<td>“we have to recognize that the process of being assessed and, as it were, having the disease and the status of illness thrust upon you, which is how it might seem to the person concerned, is upsetting.” [8]</td>
</tr>
<tr>
<td>Underestimation of the relatives’ experiences and assessments of the person with dementia</td>
<td>7, 9, 11</td>
<td>“We were told of many instances of the concerns of relatives or the person themselves that ‘something was wrong’ being incorrectly dismissed by general practitioners or hospital doctors. This left people with early dementia, and their families, without access to support.” [9]</td>
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<tr>
<td>Reasonableness of treatment indications</td>
<td>4, 14</td>
<td>“Researchers do not dispute the modest benefits of cholinesterase inhibitors in treating cognitive impairments. There is also wide acknowledgement that many individuals do not respond. Clinicians are faced with a ‘sense of hope’ they gain from prescribing something that might have some minimal effect on some unidentifiable subgroup, and the ‘despair of having no treatment options at all’.” [4]</td>
</tr>
<tr>
<td>Overestimation of the effects of current pharmaceutical treatment options</td>
<td>1, 9, 14-16</td>
<td>“A risk-benefit assessment further encourages the person carrying it out to consider the risks of not providing or permitting the activity in question: for example the risks of walking outside or alone should be weighed against the risks of prolonged sitting, boredom and frustration.” [19]</td>
</tr>
<tr>
<td>Not considering information from the patient’s relatives</td>
<td>9, 17-19</td>
<td>„We do not provide enough information. The additional information that comes from family members, namely that the patient forgets the names of his children or other pertinent personal information like his age, directs attention to dementia.” [7]</td>
</tr>
<tr>
<td>Adequate appreciation of the patient</td>
<td>1, 3, 7, 9, 11, 20-24</td>
<td>„The radical differentiation between the formality intact or ‘then’ self and the currently demented or ‘now’ self, as put forward by some commentators, is simply a mispresentation of the facts. The reality is that until the very advanced and even terminal stage of dementia, the person with dementia will usually have sporadically articulated memories of deeply meaningful events and relationships enconced in long-term memory. […] This is why it is essential that professional caregivers be aware of the person’s life story, making up or losses by providing cues toward continuity in self-consciousness. Even in the advanced stage of dementia… one finds varying degrees of emotional and relational expression, remnants of personality, and even meaningful non-verbal communication (as in the reaching out for hug).” [22]</td>
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<td>Insufficient consideration of existing preferences of the patient</td>
<td>1, 8, 9, 11, 14, 15, 21, 24-34</td>
<td>“Doctors often rate the quality of life of the patient as lower than the patient perceives it, and the life itself of lower value than the patient rates it. The only way to face ethical dilemmas about treatments is to ask the patient about their perception of their quality of life and their treatment preferences.” [29]</td>
</tr>
<tr>
<td>Problems concerning understanding and handling of patient autonomy</td>
<td>1, 9, 10, 24, 35, 36</td>
<td>“Protecting negative rights is insufficient. People with dementia need positive rights - support from social care (such as help with communication and decision-making) - to enable them to exercise autonomy.” [35]</td>
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<td>“A second factor to be considered when applying the principle of respect for autonomy is that the locus of decision making must be the patient. There are cases in which what is in the patient’s best interest may be contrary to the wishes of the family. Although it is extremely rare for families not to want what is best for the patient, the family’s understanding may be inaccurate or incomplete.” [24]</td>
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### 2. Assessing patient decision-making competence (PDMC)

<table>
<thead>
<tr>
<th>Problematic aspects in PDMC</th>
<th>Ref.</th>
<th>Quotations for illustration</th>
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<tbody>
<tr>
<td>Ambiguity in understanding competence</td>
<td>[1, 8-10, 20, 21, 36-41]</td>
<td>“In answering the question of whether the person is unable to make the decision, you should seek to understand whether the person: has a general understanding of the decision that they need to make and why they need to make it; has a general understanding of the likely consequences of making or not making this decision; is able to understand, retain and weigh up the information relevant to the decision; can communicate their decision (by talking, using sign language or any other means)” [38]</td>
</tr>
<tr>
<td>Problematic aspects in PDMC</td>
<td></td>
<td>“It is also paradoxical that respect for autonomy might involve respecting the non-autonomous decisions of the person: ‘non-autonomous’ in that they are made - in the case of some - without insight and without the requisite capacity for the person to exercise true autonomy.” [8]</td>
</tr>
<tr>
<td>Inadequate assessment</td>
<td>[1, 6, 9, 21, 41-43]</td>
<td>“Many patients with dementia are ambulatory, respond to stimuli, and are able to communicate, even if in a rudimentary manner.” [42]</td>
</tr>
<tr>
<td>Inadequate consideration of setting or decision content</td>
<td>[1, 9, 10, 43, 44]</td>
<td>“Clinicians also should be mindful of the possibility of incapacity in patients in certain settings, namely long-term care facilities, medical-surgical inpatient units, and hospice. The evaluation of a capacity is distinct from the evaluation of the overall competence to manage one’s affairs, in that the latter involves a formal judicial process, including the selection of a guardian.” [10]</td>
</tr>
<tr>
<td>Disregarding the complexity of assessing authenticity</td>
<td>[1, 9, 21, 39, 45, 46]</td>
<td>„In determining the validity of living wills the physician cannot call into question the authenticity of a living will merely with the argument that a decision is “unreasonable”, or by pointing out that “better” medical treatment is possible. Many authentic decisions made by individuals exercising their selfdetermination may seem to be unreasonable, whereas they do not violate the right of self-determination in a democratic society.” [45]</td>
</tr>
<tr>
<td>Underestimation of the relatives’ experiences and assessments of the patient</td>
<td>[7, 9]</td>
<td>“Already in the early stages of dementia, questioning the patients relatives or trusted acquaintances about the decline of their cognitive abilities or the deterioration of performance can help confirm the diagnosis.” [7]</td>
</tr>
</tbody>
</table>

### 3. Information and disclosure

<table>
<thead>
<tr>
<th>Ref.</th>
<th>Quotations for illustration</th>
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<tbody>
<tr>
<td>Respecting patient autonomy in the context of disclosure</td>
<td>[1, 9, 10, 15, 20, 37, 41, 44, 47]</td>
</tr>
<tr>
<td>Adequate amount and manner of information</td>
<td>[1, 9, 11, 13, 15, 20, 21, 44, 47]</td>
</tr>
<tr>
<td>Adequate involvement of relatives</td>
<td>[9, 13, 43, 44]</td>
</tr>
<tr>
<td>Consideration of cultural aspects</td>
<td>[9, 43]</td>
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### 4. Decision-making & consent

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<thead>
<tr>
<th>Ref.</th>
<th>Quotations for illustration</th>
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<tbody>
<tr>
<td>Improvement of patient decision making competence (PDMC)</td>
<td>[17, 20, 33, 37]</td>
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Spectrum „Clinical Ethics in Dementia Care“ EthicsGuide 2
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<tr>
<th>Topic</th>
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<tbody>
<tr>
<td>Risk of insufficient conditions for fostering decision-making capacity</td>
<td>Reduce the emotional pressure associated with the decision. This pressure may be intrinsic to the decision - all possible options may seem equally frightening, for example. Or it may come from external sources, such as conflicting views among different family members.” [1]</td>
<td>[1, 9, 10, 48]</td>
</tr>
<tr>
<td>Risk of disregarding the need of continuous relationship-building with the patient as a means to foster patient autonomy</td>
<td>„the therapeutic relationship should not only respect, but actually promote the autonomy remaining during the different phases of the disease in order to define shared existential, therapeutic and welfare objectives, and avoid ‘automatic’ decisions and practices relating (for example) to institutionalization and life support treatments.” [37]</td>
<td>[1, 9, 20, 37]</td>
</tr>
<tr>
<td>Risk of setting the time for decision-making processes too short</td>
<td>“Perhaps the most important issue is time. People with dementia cannot be rushed into decisions and a structured, clear approach by a person or persons can go a long way towards bringing about a resolution where the affected person is expressing wishes that are not in their family’s best interests.” [9]</td>
<td>[1, 9]</td>
</tr>
<tr>
<td>Risk of weakening PDMC by infantilization</td>
<td>“Interactions with professional caregivers may also silence the person with dementia and sometimes also family members […] This is especially true if sufferers perceive that they are not taken seriously or are ignored or treated like children” [11]</td>
<td>[9, 11]</td>
</tr>
<tr>
<td>Responsible surrogate decision-making</td>
<td>Adequate handling of „best interest“ and „substituted judgments“ decisions</td>
<td>Surrogates face a number of additional challenges. For example, a study of 81 surrogate decision-makers found that only 73% had correctly identified their family members’ resuscitation orders, and only 47% demonstrated good understanding of the clinical situation. […] Family members of patients who had advanced dementia identified the following barriers to surrogate decision-making: unrealistic expectations of patients, not having had discussions with patients about preferences (or waiting too long to do so), and patients’ denial of dementia.” [10]</td>
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<td></td>
<td>Inadequate communication with relatives</td>
<td>“is important that the quality of the relationship between the health care provider and the family caregiver can also be crucial to the provision of care for PWDs and has been shown to assume great importance in situations such as the considerations of end-of-life decision making in the long-term care setting.” [3]</td>
</tr>
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<td></td>
<td>Inadequate handling of information stemming from relatives</td>
<td>„The central problem in this case was that there were conflicts of opinion within the family and between the family and the physician.” [64]</td>
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<td></td>
<td>Need of advanced planning</td>
<td>“While the role of family and carers is often crucial to safe care of such older patients, it is very important that the wishes and views of older people are not bypassed in favour of family members or carers.” [19]</td>
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<td></td>
<td>Risk of disregarding legal clarifications</td>
<td>“Certain difficult decisions will require a declaration from the court that the treatment is indeed in the patient's best interest.” [1]</td>
</tr>
<tr>
<td>Adequate consideration of living wills/advance directives</td>
<td>Challenges in interpreting the living will/advance directive</td>
<td>„Some people consider life with dementia to be worse than death and they write advance directives to make sure they will not receive any life-prolonging treatment in the event that they become demented. When they indeed do become demented, however, they may appear tranquil and happy, and it may seem absurd to say that their lives are terrible or that it is better for them not to receive life-prolonging treatment anymore.” [65]</td>
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<td></td>
<td>Challenges in deciding to follow or not to follow the content of the living will/advance directive</td>
<td>“Doubts can arise concerning the competence of the subject at the time the document was drawn up or the amount and type of information given to him/her at that time. Furthermore, changes in the therapy (and therefore the prognosis) of the disease between the time the directives were formulated and the time they are applied may be such as to completely overturn the premises underlying the decision.” [37]</td>
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<td>“the Best Interest Standard sets rigorous limits to the bindingness of ADs in two substantively different but formally related dementia modalities: (1) An AD requests that no lifesaving measures be used but the patient is not demented and faces an acute life-threatening disorder that is easily treated through non-burdensome, minimally invasive procedures. (2) An AD requests that all possible lifesaving measures be used but the patient is painfully demented and suffers from a severe disorder that can only be treated, if at all, through very burdensome, highly invasive procedures.” [52]</td>
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<td>“advance directives represent a solid moral basis on which to take medical decisions concerning a patient who has become incompetent, especially when such decisions involve choices between medical possibilities of which none has been demonstrated to be certainly more valid or between different or even conflicting values.” [37]</td>
</tr>
</tbody>
</table>
## 5. Social and context-dependent aspects

<table>
<thead>
<tr>
<th>Activity</th>
<th>Ref.</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Caring for relatives</td>
<td>[1, 7, 9, 11, 18, 20, 21, 43, 61, 62, 66-68]</td>
<td>“Dementia care should clearly further the life of the person with dementia. However, significant others should also be taken into consideration in the goal of care.” [62]</td>
</tr>
<tr>
<td>Caring for clinical personnel and professional carers</td>
<td>[9, 21, 62, 69-72]</td>
<td>“Flexibility is therefore an important ingredient, not only in the care process of residents, but also in the administration of staff members in nursing homes.” [70]</td>
</tr>
<tr>
<td>Assessment of the patient’s potential to (direct or indirect) harm to others</td>
<td>[16, 17, 43, 73]</td>
<td>„The presence of cognitive disorder or severe mental illness, however, raises the possibility that the person engaging in a high risk activity or behaviour does not have the capacity to make decisions related to its riskiness. When questions of safety arise in individuals with cognitive impairment or severe mental illness at any age, the clinician should either perform an assessment of capacity or refer the person for an assessment of their capacity to determine the specific issue at hand.” [43]</td>
</tr>
<tr>
<td>Responsible handling of costs and allocation of limited resources</td>
<td>[1, 4, 9, 10, 17, 74]</td>
<td>“neuroimaging is expensive and labor intensive so that it is important to consider whether this allocation of resources is worth the cost with respect to informing clinical decision making at the individual or societal level. There are times where the rights of the individual are weighed more heavily than those of society.” [74]</td>
</tr>
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</table>

## 6. Care process & process evaluation

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<tr>
<th>Activity</th>
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<th>Quotations for illustration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuing assessment of potential benefits and harms</td>
<td>[9, 14-16, 75]</td>
<td>“Most obviously we should try not to do things which cause harm, but we may also be obliged to stop or prevent processes which are causing harm to an individual.” [15]</td>
</tr>
<tr>
<td>Adequate patient empowerment</td>
<td>Patient-oriented setting</td>
<td>[7, 9, 17, 19, 20, 76]</td>
</tr>
<tr>
<td>Activation of patients</td>
<td></td>
<td>[7, 11, 12, 77]</td>
</tr>
<tr>
<td>Self-reflection of carers</td>
<td>Attitudes towards dementia patients</td>
<td>[9, 17, 75]</td>
</tr>
<tr>
<td>Reflection on conflicts of interests and values</td>
<td>[9, 17, 37, 43, 78, 79]</td>
<td>“It could be that, in this style of working, there is little room for critical reflection on one’s practice. The fact that value conflicts are not experienced as being problematic does not necessarily imply that they are not problematic.” [79]</td>
</tr>
<tr>
<td>Continuing education/capacity building of the carers</td>
<td>[9, 11, 43, 69, 80, 81]</td>
<td>“Overt acknowledgment of the ethical nature of the difficulties facing carers, a willingness to discuss matters of values as well as matters of fact, some grasp of alternative ethical viewpoints to allow informed discussion - all these might make a positive contribution to the support given to carers.” [80]</td>
</tr>
<tr>
<td>Evaluation of abuse and neglect</td>
<td>[9, 10, 43]</td>
<td>“The abuse of people with dementia by people caring for them raises particular ethical issues, because of the complex relationships and dependencies involved. While definitions of abuse differ, it is widely accepted that the concept extends beyond physical or sexual abuse to psychological and emotional harm, financial exploitation and neglect.” [9]</td>
</tr>
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## 7. Special situations for decision-making

<table>
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<tr>
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</tr>
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<tbody>
<tr>
<td>Ability to drive</td>
<td>[10, 17, 20, 43, 73, 82]</td>
<td>“Such borderline cases with mild dementia must be referred to specialized driving centres for comprehensive on-road testing, and it is our society’s obligation to ensure that such testing is available in a timely and affordable manner.” [82]</td>
</tr>
<tr>
<td>Sexual relationships</td>
<td>[9, 10]</td>
<td>“Although sexual activity declines with age, a substantial proportion of older adults, including those who have cognitive impairment and those living in long-term care facilities, remain sexually active. The potential for abuse or exploitation exists, but the capacity of the older adult to consent to a sexual act has been poorly studied.” [10]</td>
</tr>
<tr>
<td>Indication for genetic testing</td>
<td>[10, 20]</td>
<td>“In dementia care, a number of challenges arise […] including (1) genetic testing of patients and family members for irreversible, neurodegenerative conditions;” [10]</td>
</tr>
</tbody>
</table>
Usage of GPS and other monitoring techniques [9, 21, 83-85]  
“the major benefits of electronic tracking using GPS systems were related to the peace of mind of the carers themselves. Although there is no basis to suspect that they did not want the best for the demented person, there is no guarantee that the demented persons would make the same choices about their lives as did their family caregivers and their professional care providers.” [83]

Prescription of antibiotics [16, 53]  
“we must ask whether the interests of the patient are being served by using antibiotics. We must further ask whether the use of antibiotics in each specific patient justifies the risk placed on others by their use” [16]

Prescription of antipsychotic drugs [9, 10]  
“Much has recently been written about the way the anti-psychotic drugs, in particular, have been overused in people with dementia, and this is of particular concern given evidence that use of anti-psychotic medicines in people with Alzheimer’s disease and dementia with Lewy bodies is associated with a shortened life expectancy” [9]

Indication for brain imaging [9, 74]  
“Moreover, it is not yet known how well these scans or CSF tests will work in larger older populations, and hence how useful they will be as an accurate diagnostic tool: a major postmornem study has found a high frequency of individuals showing significant signs of amyloid deposits, which would have appeared as ‘positive scans’, regardless of whether the person in fact experienced any signs of dementia during their life-time” [9]

Covert medication [21, 86, 87]  
“What about when the patient is given medication secretly in food or drink? It cannot be said that the person has consented to this medication. It is not only covert medication, but also coerced medication.” [21]

Restraints [8, 9, 17, 20, 37, 72, 74, 88, 89]  
“When treatment is both life-prolonging and in the patient’s best interests, there would need to be strong justification for not using restraints if restraints are essential to treat.” [88]

Tube feeding [9, 10, 17, 20, 21, 30, 42, 43, 54, 63, 90-92]  
“There is no evidence that a PEG generally achieved any of the desired treatment goals. False hopes and expectations for family members and caregivers had to be corrected. [...] The crucial question in the treatment of patients with advanced dementia should not be, PEG or not PEG?, but: What are the most important preferences of the patient that fit into their concept of life and that they receive an appropriate palliative treatment (adequate space, care, and the proximity of confidants, etc.)?” [63]

End of Life / palliative care [9, 20]  
“there is evidence that people with dementia experience poor care at the end of their lives, with badly controlled pain, little control over the place and manner of their death, and significant stress on their carers. Moreover, recent research in the UK has suggested that amongst older people who die in hospital, those who have dementia are less likely to receive palliative medication, are less likely to have attention paid to their spiritual needs, and are less likely to be referred to palliative care specialists than people who do not have dementia” [9]

Suicidality [28, 46]  
“studies show, that many individuals with dementia enjoy human interaction, physical and mental activity, and other aspects of living even as the disease progresses. Thus, the comment I hear from many cognitively intact adults, ‘I wouldn’t want to live that way,’ does not seem to be true for the majority of people who develop dementia.” [28]

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