

Review article

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

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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.^{1,2} 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.^{3–6} To date, the British Nuffield Council on Bioethics report *Dementia: Ethical Issues* is probably the most extensive.² 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.⁷ 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.⁸

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

taken into account when drafting normative recommendations on the basis of the results of the review.

Method

Literature search and eligibility criteria

We searched in Medline using the following search algorithm: (((("Ethics"[Mesh])) OR ("ethics"[ti])) OR ("ethical"[ti])) AND (((("Dementia"[Mesh])) OR ("Dementia"[ti])) OR ("Alzheimer's Disease"[ti])) OR ("Alzheimer Disease"[ti])). The search was restricted to English and German language literature and to publications from 1 January 2000 to 31 January 2011. We searched in Google books with the search string "Dementia AND ethics". Because of the vast number of hits (12 200) and because Google books listed 'most relevant' hits at the top of the list, we focused on the first 100. The ordering for relevance had face validity as we found, among these first 100 hits, many textbooks and monographs that dealt with dementia and ethics we were aware of. No search restrictions were used for the Google books search. The Discussion explains and justifies why we restricted our literature search to Medline and Google books.

For the definition of DSEI we referred to the ethical theory of principlism⁹ that forms the basis of many ethical and medical professionalism frameworks.^{10,11} Principlism is based on the four principles of beneficence, non-maleficence, respect for autonomy and justice. These principles represent *prima facie* binding moral 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.

Paragraphs 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.^{3-6,12} 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 disavowing 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'.³ 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

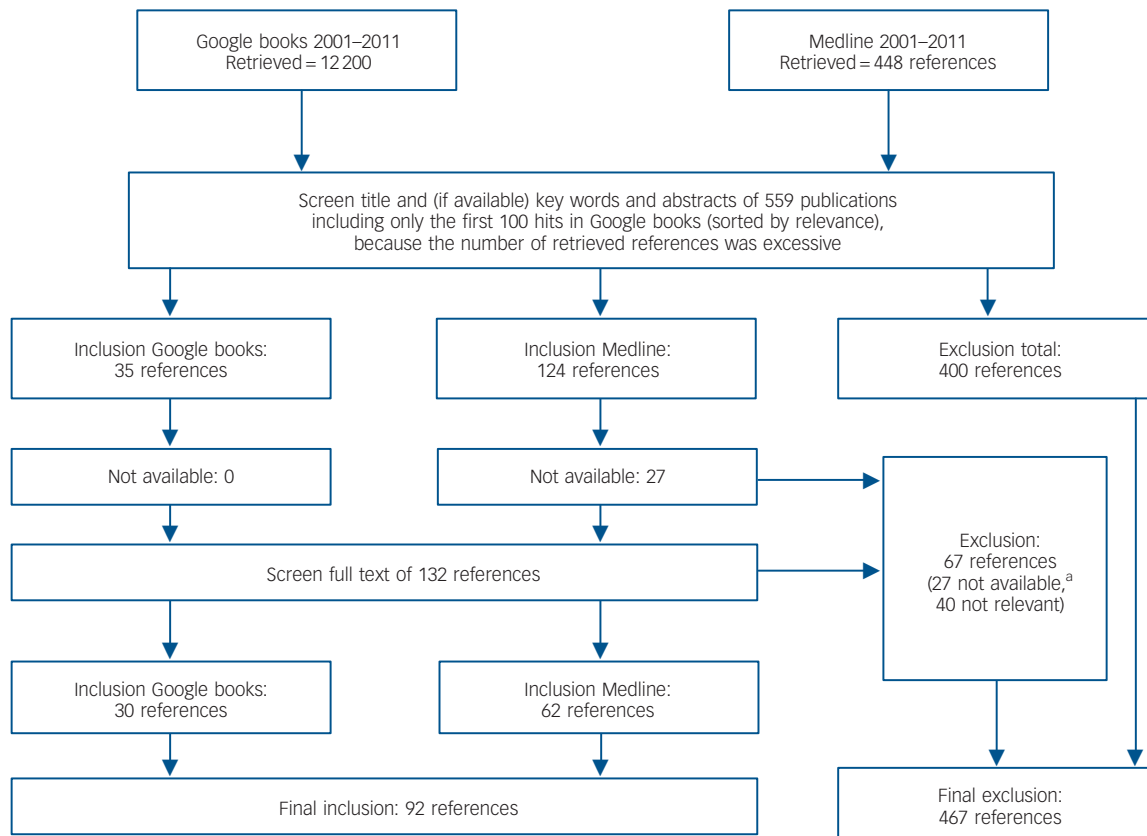


Fig. 1 Flow chart for inclusion/exclusion of references.

a. A reference was classified as being ‘not available’ in cases where we did not have access to the paper and where the authors did not respond when we asked them to supply a copy.

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).

	References, <i>n</i> (journals, <i>n</i>)
Publication type	
Journal articles	62
Book chapters	20
Books/reports	10
Language	
English	78
German	14
Field of journal	
Medicine/gerontology/palliative care	22 (14)
Ethics/philosophy	22 (11)
Psychiatry/neurology/psychology	11 (11)
Nursing/caring	6 (5)
Social science	1 (1)
Total	62 (42)

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 reporting⁷ or narrative book-length descriptions.^{2,14} 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.^{15,16} 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,^{3,17} topic-specific monographs^{14,18} and comprehensive reports such as the Nuffield Council on Bioethics report on dementia.² 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.*¹⁹ 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.^{20–23}

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 choose 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.²⁰

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.²⁴ 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'.² 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 *v.* respect of autonomy):

'(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?'²

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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Appendix

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^{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 person with dementia^{2,30,31}

Adequate point of making a diagnosis:

- Risk of disavowing signs of illness and disregarding advanced planning^{3,12,31,32}
- 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^{27,34}
- 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^{2,3,6,14,26,30,31,38–40}
- Insufficient consideration of existing preferences of the patient^{2,3,14,17,31,34,35,40–50}
- Problems concerning understanding and handling of patient autonomy^{2,3,12,40,51,52}

2 Assessing patient decision-making competence

Ambiguity in understanding competence^{2,3,6,12,14,17,52–57}

Problematic aspects in patient decision-making competence:

- Inadequate assessment^{2,3,4,14,29,57,58}
- 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^{2,3,6,12,35,53,57,59,62}
- Adequate amount and manner of information^{2,3,6,14,31,33,35,59,62}
- Adequate involvement of relatives^{2,4,33,59}
- 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^{2,31}

Responsible surrogate decision-making:

- Adequate handling of 'best interest' and 'substituted judgements' decisions^{2–4,6,12,14,17,35,40,51,52,55,64–71}
- 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^{2–6,12,48,75}
- Risk of disregarding legal clarifications^{2,3,6}

Adequate consideration of living wills/advance directives:

- Challenges in interpreting the living will/advance directive^{3,6,41,53,60,66,70,80}
- Challenges in deciding to follow or not to follow the content of the living will/advance directive^{2,4,14,35,53,66,67,70}

5 Social and context-dependent aspects

- Caring for relatives^{2,3,4,6,14,18,30,31,76,77,81–83}
- 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^{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^{2,34–36,90}

Adequate patient empowerment:

- Patient-oriented setting^{2,5,6,30,37,91}
- Motivation of patients^{30,31,32,92}

Self-reflection of carers:

- Attitudes towards patients with dementia^{2,5,90}
- Reflection on conflicts of interests and values^{2,4,5,53,93,94}
- 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 genetic testing^{6,12}

Usage of GPS (global positioning system) and other monitoring techniques^{2,14,98–100}

Prescription of antibiotics^{36,68}

Prescription of antipsychotic drugs^{2,12}

Indication for brain imaging^{2,89}

Covert medication^{14,101,102}

Restraints^{2,5,6,17,53,87,89,103,104}

Tube feeding^{2,4–6,12,14,46,58,69,78,105–107}

End of life/palliative care^{2,6}

Suicidality^{44,61}

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