Ethics support in institutional elderly care: a review of the literature

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ABSTRACT

Clinical ethics support mechanisms in healthcare are increasing but little is known about the specific developments in elderly care. The aim of this paper is to present a systematic literature review on the characteristics of existing ethics support mechanisms in institutional elderly care. A review was performed in three electronic databases (Pubmed, CINAHL/PsycINFO, Ethxweb). Sixty papers were included in the review. The ethics support mechanisms are classified in four categories: 'institutional bodies' (ethics committee and consultation team); 'frameworks' (analytical tools to assist care professionals); 'educational programmes and moral case deliberation'; and 'written documents and policies'. For each category the goals, methods and ways of organising are described. Ethics support often serves several goals and can be targeted at various levels: case, professional or organisation. Over the past decades a number of changes have taken place in the development of ethics support in elderly care. Considering the goals, ethics support has become more outreaching and proactive, aiming to qualify professionals to integrate ethics in daily care processes. The approaches in clinical ethics support have become more diverse, more focused on everyday ethical issues and better adapted to the concrete learning style of the nursing staff. Ethics support has become less centrally organised and more connected to local contexts and primary process within the organisation.

INTRODUCTION

In 1985, Eileen and Don Curl[1] expressed their hope that one day long-term care, which includes residential elderly care, would not be the 'forgotten' setting of ethical dilemmas. Since then a lot has changed. Nowadays it is widely recognised that ethical issues in elderly care exist and that its context differs from acute care. Differences lie in the care-receiver, the organisational context (including staff characteristics) and the kind of ethical issues that arise.[2 3] Residency in a nursing home usually lasts for a longer period and residents are confronted with long-term dependency on others.[2 3] Staff is confronted with end-of-life-issues, and with the ethical issues that are hidden in everyday life in the institution.[4–6] It is generally acknowledged that ethical issues in elderly care need to be addressed. Ethics support is a collective term for various mechanisms to help healthcare professionals in dealing with the ethical issues they face in their daily practice. This paper presents an international literature review of the ethics support forms specifically developed for residential (nursing homes and care homes) and semiresidential (day care) elderly care, over the past three decades. Our main research question was: "What types of ethics support mechanisms are described in the literature and what are the goals, methods and ways of organizing of this support?" We classified the types into four categories and described the goals, methods and ways of organising for these categories.

This overview intends to give elderly care institutions and their staff members insight into current mechanisms for ethics support. Furthermore, it reveals historical developments in ethics support in elderly care which provides the opportunity to learn from the past.

METHOD

Search procedure

To identify studies on ethics support in elderly care a systematic search in three different electronic databases was performed: Pubmed, CINAHL/PsycINFO and Ethxweb. The search was limited to English and Dutch publications from January 1980 until October 2011. Related to the two key concepts, '(semi) residential elderly care' and 'ethics support', a list of equivalent search terms (see table 1) was formed, using both subject headings (Mesh terms, Cinahl headings) and free search terms.

Selection process

The selection of relevant articles took place in several steps (see figure 1). The search in the three selected databases yielded 3.936 publications (including overlap). The high number of hits was a consequence of the broadness of our research question and search procedure. We deliberately chose a wide lens since 'ethics support' is not a standard search term. Furthermore, we wanted to look at ethics activities and products that were not directly archived or recognised as being 'ethics support'.

Authors SvdD and BM screened titles and abstracts with the following inclusion and exclusion criteria. Included were articles that describe a form of ethics support for professional caregivers, who work in a residential or semiresidential elderly care setting. Excluded were articles about other residents or patients than older people; residents or family members who experience moral problems and articles on one specific type of moral issues or research ethical issues. This process resulted in 158 potentially relevant publications for further reading. After close-reading of these articles, using the same inclusion and exclusion criteria, 60 publications were included for the final review (see online supplementary appendix 1 for a categorisation of the references).

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Table 1 Search terms

Key concept 1: (semi) residential elderly care	Key concept 2: ethics support
MeSH/Cinahl:	MeSH/Cinahl:
▶ home[s] for the aged OR	▶ clinical ethics OR
▶ nursing home[s] OR	▶ medical ethics OR
▶ long-term care OR	▶ nursing ethics OR
▶ residential facilities OR	▶ decision making/ethics OR
▶ day care/age-specific care/long-term care OR	▶ decision making/ethical OR
	▶ decision support techniques OR
Free search terms:	▶ gerontologic nursing/ED/EI
▶ care home OR	▶ ethical analysis/methods OR
▶ day care OR	▶ geriatric nursing/ethics OR
▶ assisted living OR	▶ nursing staff/education OR
▶ elderly care OR	▶ nursing staff/ethics OR
	▶ problem solving/ethics OR
	▶ attitude of health personnel OR
	▶ ethics consultation OR
	▶ Ethics, Institutional OR
	▶ Organisational ethics OR
	Free search terms:
	▶ ethics support OR
	▶ ethical reflection OR
	▶ ethical deliberation OR
	▶ moral deliberation OR
	▶ moral case deliberation OR
	▶ ethics committee OR
	▶ reflection groups OR
	▶ ethics rounds OR
	▶ reflection/ED/EI

ED, education; EI, ethical issues.

Table 2 Types of ethics support

Category	Number of publications	Examples
1. Institutional bodies	32	Clinical ethics committee, ethics group, clinical ethics consultation
2. Frameworks	17	Step-by-step decision-making tools, values profile, folk taxonomy
3. Educational programmes and moral case deliberation	7	Ethics rounds, care-ethics lab, moral case deliberation
4. Written documents and policies	4	Policy (including patient directive form), ethics code (and guide)

Analysis

The included articles (N=60) cover a wide range of ethics support. Analysing the papers through content analyses and subsequent discussions in the research team resulted in a categorisation consisting of four categories representing different types of ethics support (see table 2).

The four categories were empirically constructed, based on the literature search, and reflect the 'landscape' of ethics support mechanisms in residential elderly care. The purpose of our category system is to elucidate specific characteristics of, and differences and similarities between various types of ethics support. Further analysis concentrated on the following dimensions of the four categories: goals, methods and ways of organising. 'Goals' refer to the specific focus of ethics support (eg, the ethical issue or the healthcare professional) and to the intended outcomes (eg, sound ethical decision making or raising moral awareness). 'Methods' refer to the technique that is applied in order to reach the goal (eg, team conversations or experiential learning). 'Ways of organising' refer to how the ethics support is organised (eg, as a committee).

RESULTS

The majority of the 60 included papers regards North America (USA/Canada) and was published in the 1980s and 1990s. From 2000 publications from other countries (ie, Australia, Belgium, Sweden, Norway, the Netherlands) were also found. The publications vary considerably concerning the size, scope and

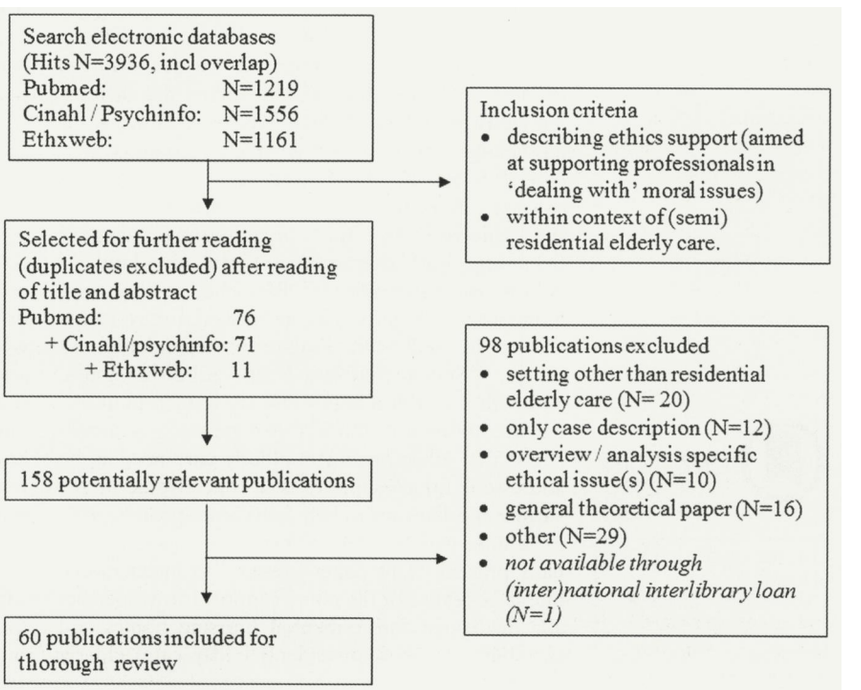

Figure 1 Flow chart of the publication search.

profundity. The publications showed quite a lot of cross-referencing. An overview of the included articles per category is presented in online supplementary appendix 1.

Types of ethics support

Below we will present the four categories of ethics support and describe goals, methods and ways of organising for each.

Institutional bodies: ethics committee and consultation team

We included 32 publications on institutional bodies: 24 on clinical ethics committees (CECs) and similar ethics groups and four on ethics consultation and mediation. Although the number of CECs has increased since the 1970s,[7 8] in the late 1980s CECs are still an uncommonly used tool of nursing homes for handling ethical dilemmas.[9] The relatively high number of publications on CECs and the increasing percentages of institutions that have established a CEC, indicate a slow but steady increase of CECs.

Goals

Most CECs serve multiple purposes, varying from a narrow focus on assisting in the decision-making process[1 10 11] to a broader scope of fostering an institutional milieu that is sensitive to ethical priorities.[7] Early publications also refer to a legal base, pointing at developments in the 1980s (eg, the passage of the Natural Death Act in 1983) which motivated institutions to establish a CEC.[3 12 13] The goal of these CECs was to minimise the possibility of litigation and liability[10] or to raise issues with residents and their families and give them the opportunity to exercise their rights.[14] The most common goals of CECs are: education of staff (and sometimes also residents, their family and the community); development of policies and guidelines; and case review (prospective or retrospective).[7] Although research indicates that 25–30% of the CECs have decision-making authority,[9] all articles in our review underline the advisory role of CECs. Case review should not discharge healthcare professionals, resident and family of their decision-making responsibilities,[13] and is therefore considered consultative[3] and supplementary to customary decision making.[7]

Methods

Before they take on other activities, most CECs start with self-education,[9 12] that is, following courses, using reading material and discussing cases, and some CECs hire an ethicist.[15–17] Education of staff and others is done by, for example, organising conferences, ethics rounds, case discussions or conducting specific educational programmes. Some CECs have scheduled (monthly) meetings, set their own agenda and only discuss hypothetical cases,[15] while other CECs generate requests from the staff, resident and family or administrators.[9] Most CECs will consider exceptional issues like Do Not Resuscitate orders, patient competence, the use of feeding tubes or the use of restraints.[9] A number of CECs pay explicit attention to everyday ethical issues.[16 18 19] One article pictures the shift that the particular ethics study group made from a focus on end-of-life, medical decision issues to the ordinary, everyday events of resident life. This "opened up myriad issues (...) that usually deemed too mundane to consider seriously or outside the purview of ethics".[18] The majority of the 32 publications do not go into the method that is applied in reviewing cases, with the exception of the decision-making trees developed for case managers,[17] the framework proposed by Hogstel *et al*[11] and the mediation model presented by Wood.[20]

Ways of organising

Two-thirds of the publications on CECs describe committees that are organised in a traditional fashion: regular meetings of a multidisciplinary group (10–15 members) representing the professionals, administrators and sometimes patients, family members and/or representatives of the community.[9] The way CECs are organised has been criticised over the past decades. It is said that CECs may create undesirable bureaucracy, are not close enough to the clinical situation and too passive,[21] and may diffuse responsibilities.[9 22 23] Alternatives for the traditional CEC have been presented in the literature, reflecting a number of changes. In the first place a liaison with quality assurance is made.[3 24] According to Piette *et al*[23] a 'next generation CEC', who integrates ethics in quality improvement, makes "ethics and values become a part of what every person does every day, rather than being present only in formal ethics decisions"(p. 42). In the second place a more outreaching form of ethics support is provided by the ethics consult team, smaller and more flexible than the typical CEC, having the ability to assemble with relative ease and go to the bedside when needed.[22 25] This consult team is part of a centre on ethics, which illustrates a third development in the way CECs are organised: decentralisation and specialisation of CEC functions, which is also found in the Capital Health Ethics Support model, described by Simpson *et al*.[26] A fourth development that is visible in integration with quality assurance and the centres on ethics is a broadening of the scope from resident care issues to organisational ethics, as "the place of ethics will be found equally at the bedside and in the boardroom".[26] Overall, with these developments the role of traditional centrally organised CECs has transformed more into a network organisation.

Frameworks

In 17 publications we found 12 different examples of frameworks. Frameworks are analytical tools to assist care professionals in dealing with and solving ethical problems.[i] Typically, a step-by-step approach is used.

Goals

The focus of frameworks is on the case level. Most frameworks are illustrated with problems that surround end-of-life care, use of restraints, tube-feeding, informed consent and decision-making capacity.[27–29] One framework is applied to problems in processes of admission, relocation and transfer.[30 31] Three frameworks pay explicit attention to everyday ethical issues that arise in the context of nursing home life.[4 5 32–35]

The main goal of using a framework, especially a step-by-step approach, is to resolve ethical problems that arise in practice. Several authors point out that the process of coming to a decision is just as important as the resulting decision. A framework serves to 'find moral agreement in the midst of differing moral beliefs and traditions'.[27] Pompei stresses the importance of 'dialogue' and 'working through the dilemma'[29] and Schneider concludes that "dilemmas do not disappear simply because this model is employed; however, it will provide a framework for stimulating critical thinking and ethical reflection".[30] The use of a systematic approach helps to safeguard against personal biases,[36] and increases the likelihood that healthcare professionals explore the most important aspects of the case.[29]

[i]The term 'framework' is borrowed from Pompei [33]. Examples of other terms that are used are: process [Hamilton], model [Miedema] or template [Kirsch].

Thoughtful deliberation of ethical issues warrant the trust of patients and society in healthcare providers.[37] In addition, using a framework reduces complexity and uncertainty,[31] as decisions that are well-considered and well-founded likely will reduce moral stress by giving good reasons for what to do.[32] Two frameworks, Sansone's *values profile* and Power's *folk taxonomy*, do not follow a step-by-step-approach and focus not on decision making but rather on mapping out the resident's values[35] or raising awareness of the ethical implications of common everyday situations.[5]

Methods

The step-by-step frameworks roughly follow the same sequence of elements: (1) recognition and definition of the ethical issue, (2) consideration of the relevant facts, (3) assessment of stakeholders and value judgments, (4) assessment of alternatives and consequences, (5) decision and implementation, and (6) evaluation. Some frameworks are explicitly shaped by an underlying ethical theory, for example, the teleological model described by Bolmsjö *et al*[4 32] or the casuistic framework suggested by Slettebø. Most frameworks are not directly derived from one ethical theory. The authors discuss different ethical theories as a basis for moral reasoning; they present their framework as a practical tool for guiding reflection and deliberation. Ethical principles are not a standard component: in seven frameworks they are absent. To some authors, ethical principles are indispensable as 'guideposts in the decision-making process'.[30 31 38] Other authors regard a principle-based approach too rationalistic or too abstract and therefore not very helpful to professionals when dealing with everyday ethical problems.[32 38] Slettebø and Horner present their framework as supplementary to a principle-based approach.[38 39]

Evaluation of a decision is important in order to see whether the solution has in fact improved the good lives of the involved parties on the whole,[32] to prevent or reduce the effects of collateral damages[37] and to be able to adjust the decision to changed circumstances.[27 28]

Ways of organising

In general, the frameworks are meant to be used by healthcare professionals when deliberating on ethical problems that they are confronted with. Although most publications leave it open by whom the framework can be used, some authors indicate users, for example social workers,[39] physicians,[29] nursing students,[40] a nursing team,[28 32 36 38] a multidisciplinary team[27 41] or a CEC.[33] Bolmsjö and Scheider stress the importance of implementing the presented framework together with education, taking care of time and supervision.[30–32] According to Fleming his framework requires no formal training in ethics, making it cost-effective and available for a broad range of learners: providers, managers and administrators.[27 41] Fleming and Schneider regard their framework as a (temporary) stopgap, when other formal kinds of ethics support are not (yet) available.[27 30 31 41]

Educational programmes and moral case deliberation

Educational programmes can be initiated by a CEC but may also derive from a separate institutional programme or project without any institutional body. In our review seven publications with an emphasis on education were included: five on four different educational programmes (seminars; ethics rounds; the 'Decisions near the end of life programme' and the sTimul 'Care ethics lab') and two on moral case deliberation (MCD).

Goals

The main target of educational programmes is the healthcare professional. The aims are broader than solely the development of ethical reasoning. First, professionals need to become aware of the ethical dimension of care.[42] Then, ethical reasoning is linked to everyday practice, where behavioural skills and decision-making processes employed by clinicians are important.[43] Generally this is done by using a case-driven approach. Most educational programmes emphasise the institutional context in which the professional operates. In addition, most programmes aim to foster multidisciplinary exchange and open communication. This focus on the institutional context and intercollegial cooperation also serves to contribute to an ethical climate with attention to and openness for values and norms. MCD has a strong educational focus, but it can also be applied for solving cases.

Methods

Most educational programmes focus on real, experienced ethical problems, either actual cases or cases from the past. They make use of professionals' experiences in caring for residents. Some programmes start with one or more introductory meeting(s) explaining ethical concepts and principles[42 43] before cases from practice are discussed. Ethics rounds and MCD are based on actual cases, but they are different considering the method and setting. Ethics rounds are open to all staff and attract a large and diverse audience. After the clinical case presentation, the resident and/or family are interviewed, followed by an ethical comment (by a staff member or ethicist). Then the full staff discussion takes place, concluding with a formal presentation of an ethicist, usually an outside expert.[44] In MCD, deliberations take place in smaller groups. A trained facilitator structures the deliberation, using a conversation method in order to foster joint reflection and dialogue among participants. The facilitator does not present his/her own ethical analysis to the group.[45] The care-ethics lab takes the focus on professionals' embodied experience a step further, making the professional step in to the resident's shoes. For 1 day and night they receive care from nursing students and afterwards both groups reflect on their experiences together.[46]

Ways of organising

Most programmes have a strong connection with the institutional context. The focus is on the institution as a whole, for fundamental and strategic reasons. A programme involving multidisciplinary groups is better suited for contributing to an ethical climate than teaching individual professionals. In addition, being part of a larger movement and commitment of administrators makes professionals more likely to change their attitudes and behaviours.[43] The 'decisions programme' and the 'ethics rounds' are part of an overarching centre of ethics. MCD is strongly organised bottom-up, but commitment of the management is essential to secure preconditions and stimulate a working environment in which dialogue can flourish.[6] MCD can be organised in existing teams or in mixed groups.[45] The educational programme described by Paier and Miller[42] offers a two-pronged approach, with seminars for professionals and a separate trajectory for residents and their families. The care ethics lab forms an exception with its laboratory-like context outside of the institution, although the follow-up meeting is focused on participants' experiences in their own practice.

Written documents and policies

Many publications on CECs and frameworks mention written documents and policies, sometimes as a product of a CEC. However, surveys showed that 40–60% of the institutions without a CEC also rely on written documents (such as institutional policies or guidelines) for support when ethical problems arise.[7 9] We found four publications that focus on written documents and policies. Three publications describe a policy and one publication describes a code of ethics and a guide.

Goals

The policies described by Feinsod and Levenson,[47 48] and Uhlmann *et al*[49] aim to standardise and systematise the decision-making process in order make ethical decision-making more effective, reflecting patients' wishes or best interests[47] and helping to reduce civil liability.[48] Principles and practices are presented to guide physicians and other healthcare providers. Patient-directive forms and practical suggestions are given for opening a conversation with the patient on his/her preferences.[49] One publication, from the Australian government, concerns a code of ethics and a guide to ethical conduct for providers in the Australian 'aged care sector' in order to protect the rights of residents. In addition, it provides a basis for individual organisations to develop their own written protocols.[50]

Methods and ways of organising

Written policies and documents are support mechanisms that provide basic guidance for ethical decision-making. Codes of ethics are generally formulated in an abstract, general way and are not meant to serve as a methodology for decision making in concrete situations.[37] A code therefore serves as a background document. Protocols or forms serve as practical instruments in standardising procedures and are used to document preferences.

DISCUSSION

Our review of the literature demonstrates a great variety of types of ethics support mechanisms in elderly care. We ordered the types into four main categories. Figure 2 visualises these categories.

A limitation of this literature review is that the search is limited to English and Dutch publications. We may have missed relevant publications written in other languages (eg, French, German, Italian and Spanish), and institutional reports or texts from locally or non-indexed journals or books. Another limitation is that we had to choose various search terms, since ethics support mechanisms are not yet well defined in relevant Mesh terms.

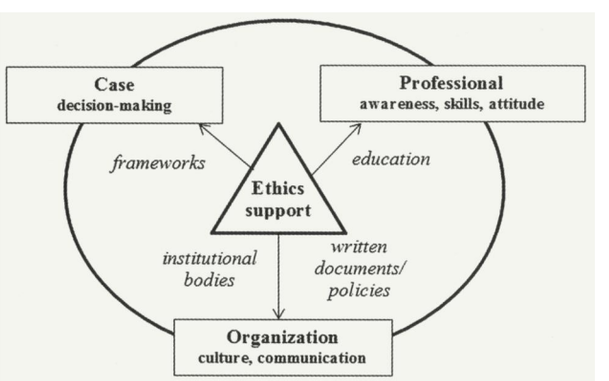

Figure 2 Interrelated elements in ethics support.

The size of the four categories does not necessarily correspond to the degrees of usage in practice. The large number of publications on CECs in the 1980s and 1990s, in combination with relatively low CEC prevalence figures,[9] is presumably a consequence of the fact that CEC was a new phenomenon at that time. The large number of publications from the USA and Canada suggests that ethics support started as an American phenomenon. Nowadays CEC in elderly care is also strongly represented in Europe.

In addition to this quantitative information the review reveals some qualitative developments in ethics support in elderly care. These developments have taken place within the traditional category of CECs (ie, committee and consultant), and also within new types of ethics support.

Considering the goals, the focus has broadened from the classical CEC functions of analysing exceptional cases and providing general guidelines, towards supporting healthcare professionals directly with their own decision-making processes. In other words, ethics support has become more outreaching and proactive.[23] Examples are easily accessible ethics rounds, which attract a large and diverse audience,[44] and consult teams, which are more flexible and outreaching.[25] As compared with CECs the categories 'frameworks' and 'educational programmes' are even more strongly focused on the healthcare professional, providing *them* with tools and competence in order to deal with *their* cases. Overall, there seems to be a change in focus from a more traditional ethics support service (performed as an analytical and expert based specialty) towards a more deliberative and contextual approach to ethics, placed at the daily level of the professional within his workplace.

The spectrum of methods has become larger and more diverse. This is probably related to a growing diversity of needs for ethics support in elderly care and a different understanding of what counts as an appropriate ethics support mechanism. Most publications included in our review emphasise the differences between elderly care and acute care. Yet, institutions which introduced ethics support in the 1970s usually followed the example of acute care, copying the types of ethics support that previously had been introduced in hospitals (eg, ethics committees). More recent types of ethics support, often combining several methods, seem to match better with the kinds of workers in elderly care and the kind of ethical issues they face. In addition to stimulating multidisciplinary dialogue,[43 45 51] methods and programmes have been developed that better meet the needs and experiences of nurses and nursing aides,[32 38 46 52 53] who constitute a large part of the elderly care workforce. Furthermore, ethics support has become more open to ordinary problems and therefore better adapted to the context of elderly care, where everyday ethical issues are common but not always recognised.[5 6 18 32–34 42]

Diversity in methods and goals, and more outreaching approaches are reflected in changes in the ways ethics support is organised. First, ethics support has become more decentralised. Our review included publications from three so-called 'centres for ethics', a label we borrowed from the Jewish Home and Hospital for the Aged.[52] These centres offer a whole range of ethics support types. Some centres have developed from the traditional CEC, incorporating its functions in separate specialist bodies that are interrelated through a network structure.[26 51] Second, ethics is more integrated with quality assurance. Integration with quality activities may be less threatening for physicians who misunderstand ethics support as a sign that their clinical practice is not already ethical.[3] Also, it may improve the scores on medical outcome indicators in surveys.[23] Third, ethics

support has become more holistic : from aides to board members[26] and from resident care issues to organisational ethical issues.[23 26 43]

An issue which is not often addressed in the publications regards effectiveness, feasibility and quality of ethics support. About 25% of the papers describe empirical results related to outcomes of ethics support. Two publications provide quantitative results: a survey[19] and a quasi-experimental design.[54] Other studies made use of qualitative methods in which outcomes are described. In general, for quantitative and qualitative research on evaluation of ethics support, the design and research methods are not well explained which makes it difficult to assess the quality of the research (and subsequently the results that are presented). More empirical evaluation research and transparency about theory, design, data collection and analysis is needed in order to assess and compare the quality of the ethics support itself and the actual contribution of each kind of ethics support service to the quality of care in elderly care.

CONCLUSION

This paper provides a systematic overview of characteristics of ethics support mechanisms in elderly care. Ethics support mechanisms can be classified in four categories: 'institutional bodies' (ethics committee and consultation team); 'frameworks' (analytical tools to assist care professionals); 'educational programmes and MCD'; and 'written documents and policies'. Ethics support often serves several goals and can be targeted at various levels: case, professional or organisation. Over the past decades a number of changes have taken place in the development of ethics support in elderly care. Considering the goals, ethics support has become more outreaching and proactive, aiming to qualify professionals to integrate ethics in daily care processes. The approaches in clinical ethics support have become more diverse, more focused on everyday ethical issues and better adapted to the concrete learning style of the nursing staff. Ethics support has become less centrally organised and more connected to local contexts and primary process within the organisation.

Contributors SvdD: idea for manuscript, data collection, writing manuscript. BM: discussion throughout the process (from data collection to final version), co-writing. GAMW: discussion on idea for manuscript, data collection and co-writing of final version. TAA: discussion on idea for manuscript, data collection and co-writing of final version, final approval before submission.

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