

# Research on ethics in nursing care for older people: A literature review Riitta Suhonen, Minna Stolt, Veikko Launis and Helena Leino-Kilpi

Riitta Suhonen, Minna Stolt, Veikko Launis and Helena Leino-Kilpi Nurs Ethics 2010 17: 337 DOI: 10.1177/0969733010361445

> The online version of this article can be found at: http://nej.sagepub.com/content/17/3/337

# Published by:

**\$**SAGE

http://www.sagepublications.com

# Additional services and information for Nursing Ethics can be found at:

Email Alerts: http://nej.sagepub.com/cgi/alerts

Subscriptions: http://nej.sagepub.com/subscriptions

Reprints: http://www.sagepub.com/journalsReprints.nav

Permissions: http://www.sagepub.com/journalsPermissions.nav

Citations: http://nej.sagepub.com/content/17/3/337.refs.html

>> Version of Record - May 5, 2010
What is This?



# Research on ethics in nursing care for older people: A literature review

Nursing Ethics 17(3) 337–352 © The Author(s) 2010 Reprints and permission: sagepub.co.uk/journalsPermissions.nav 10.1177/0969733010361445 nej.sagepub.com



Riitta Suhonen

University of Turku, Turku, Finland

Minna Stolt

University of Turku, Turku, Finland

**Veikko Launis** 

University of Turku, Turku, Finland

Helena Leino-Kilpi

University of Turku, Turku, Finland & Hospital District of South-Western Finland

#### **Abstract**

The aim of this review was to analyse the empirical studies that focus on ethics in nursing care for older people, scoping the need and areas for further study. A search of the MEDLINE and CINAHL databases (earliest to August 2009) was conducted using the the keywords: ethic\* and nursing or care or caring and elderly or aged or older. After a four-stage process, 71 empirical articles were included in the review, with informants ranging from elderly people to relatives, caregivers, managers and students in care settings. The review focusses on the concepts, contexts, methods and validity of these studies. Based on the analysis, the reviewed research seems to be fragmented and multifaceted, focussing on selected issues such as autonomy, self-determination and informed consent. No large research programs or research traditions were found so it was not possible to draw any conclusions about suitable methods, study designs or instruments of measurement for use in this research area.

#### **Keywords**

care of older people, ethics, literature review, nursing

#### Introduction

In nursing ethics, care for older people has special importance.<sup>1,2</sup> Although ethical issues in health care receive much publicity, attention is rarely given to the non-dramatic, everyday ethics of health care<sup>3</sup> that influence the supply of care and care quality. The same ethical problems have been identified in many countries<sup>4-6</sup> but the nature of these everyday occurrences may be expressed differently.<sup>7-12</sup>

One reason why ethical issues in nursing care for older people are becoming more important is changes in demography. The older patient population is increasing globally, especially in western countries. <sup>13-15</sup> Linked to this ageing population is the increased need for facilities and resources, which will vary according to the

density and type of health care provided. This density varies internationally between countries, and nationally between regions. <sup>16</sup> People aged 65 years and over living in institutions or receiving care at home as a proportion of all those aged 65 and over ranges from 1% in Slovakia to over 20% in Norway. <sup>17</sup> The number of long-term care beds in nursing homes ranges from 7 to 88 per 1000 inhabitants in Organisation for Economic Co-operation and Development countries and is linked to a tendency to reduce long-term care in hospitals. <sup>17</sup> These different densities and types of provision require appropriate research to guide the improvement of health and health care in these populations. <sup>14,15</sup>

This burgeoning health care situation can also lead to nursing manpower and skills shortages, causing low morale and motivation. <sup>16</sup> These factors affect the health care environment and make care and its delivery ethically complicated and challenging. For example, during the last phase of life, many older people and their families face decisions that challenge accepted ethical principles. This may cause conflict among family members as well as health care professionals. Although commonly used ethical principles form a useful foundation for the mapping and evaluation of decision making in these circumstances, they cannot always be used to resolve clinically challenging situations in isolation. <sup>2,18</sup> Health care professionals must clearly understand the clinical state of patients for whom difficult decisions are being contemplated, and have the time and skill to perform well while acting in the best interests of their patients.

There is other evidence that ethics in caring for older people is an important issue in clinical practice. First, ethically difficult situations and issues in the care of older people have been identified. <sup>19-22</sup> Second, there is evidence that perceptions differ about ethical issues among different groups, such as health professionals, patients and their relatives. <sup>9-12</sup> Third, some studies have found that the ethical climate in health care environments can be disempowering and undervalues older patients. <sup>23,24</sup> Finally, the greater awareness of ethical problems in caring for older people helps to ensure ethically high standards of nursing care. <sup>22</sup>

In addition, older people are a particularly vulnerable group in society and have special health problems. For example, entering an institution constitutes one of the most difficult challenges for them, and may lead to increased dependency because of the reinforcing events that occur during interactions between patients and staff.<sup>25</sup> For these demographic and clinical practice reasons, empirical studies on ethical issues need to be conducted to provide information on how to resolve ethical dilemmas in nursing practice.

Nurses are a group of health care professionals who take responsibility for the everyday care of older patients. <sup>1,2</sup> They are frequently faced with ethical challenges in their work with older people in various health care settings. <sup>2,21</sup> Ethics in nursing is made explicit in care through the approach made to older persons and how they are invited into the patient–practitioner relationship. <sup>26</sup> Discussion highlighting the ethical questions posed in nursing older people, and the increased understanding of the ethically difficult situations in their everyday care, is therefore important, although it is not an easy task to initiate discussion in society about the associated ethical aspects. Considering the organizational and technological changes that have made health care a more complex system, <sup>2</sup> together with the manpower shortage caused by the increasing numbers of older people, <sup>16</sup> it is not surprising that many health care professionals are experiencing stress related to ethical dilemmas. There is also evidence suggesting that nurses in these care settings do not feel their work is respected in society. <sup>27</sup>

To be able to identify and prioritize needs in this important area of care, and also conduct useful research, we need information about the current state of research in this field. This scoping review provides an overview of the empirical research literature on ethics associated with caring for older people. It focusses on the ethical phenomena that nurses encounter in caring for older patients in different clinical contexts. This is because, despite the growing interest in clinical health care ethics, there is a dearth of empirical studies investigating the ethical elements of day-to-day clinical practice from the perspective of both older patients and care staff.<sup>28</sup>

# Aim

The aim of this study was to review and describe published empirical studies that focussed on ethics in nursing care for older people. This is a preliminary assessment of the potential size and scope of the available research literature and aims to identify the nature and extent of research evidence.<sup>28</sup> It was conducted to scope the needs and areas for further study. The following questions were set:

- What is the range of conceptual and contextual foci of current published empirical studies concerning ethics in nursing care for older people?
- What methods have been used in studying ethics in nursing care for older people?
- How was validity assured in the studies identified in the review?

### Method

This article reports the results of a systematically conducted literature review based on a critical analysis of empirical studies of ethics in nursing care for older people in different settings.

# Literature search

To identify articles for the review, a search of the MEDLINE and CINAHL databases was conducted from the earliest date possible through to August 2009. This search yielded 925 bibliographic citations. The search terms used were: ethic\*.ab and (nursing or care or caring).ab and (elderly or aged or older).ab. The use of the term ab ensures that only articles with a separate abstract are collected. The search was limited to the English, Finnish, German and Swedish languages. No time limit was applied.

# Inclusion and exclusion criteria applied throughout the retrieval process

A citation was excluded from the analysis if: (1) no empirical data were reported; (2) the study focussed on a context other than nursing care, a nursing situation or a nursing intervention; (3) the target group of the study was not an older or aged population; and (4) the study did not investigate ethical concepts.

This review is therefore concerned with publications that: (1) report the results of an empirical study; (2) focus on nursing care situations; (3) focus on care for older people and use older people, their relatives, caregivers, managers or students from settings providing care for older people as informants; and (4) focus on ethical concepts.

# Retrieval of studies for the review

The retrieval process was conducted systematically in four phases. In the first phase, 925 abstracts found in MEDLINE or CINAHL were examined against the inclusion/exclusion criteria by two researchers working independently. They discussed the results and decided which abstracts would be analysed further. A total of 174 possible studies based on abstracts met the inclusion/exclusion criteria. The remaining 707 were excluded from the review. At this stage, 44 duplicates were excluded, leaving 130 abstracts. In the second phase of the review, the two researchers re-examined the abstracts, focusing on the concepts under study: 106 studies were selected at this stage, which included two concept analyses and two reviews. A total of 24 abstracts were excluded because they did not focus on ethical concepts. This result was confirmed by a third researcher.

In the third phase of the review, the full texts of the remaining 106 articles were reviewed independently by three researchers. At the end of this phase, 35 articles were excluded because: four articles used samples

that were not concerned with caring for older people; four were not concerned with ethical concepts; 24 were not empirical studies or reviews; and three were not concerned with nursing. This left a total of 71 articles for review.

In the fourth and last stage, a systematic analysis of the 71 full text articles was conducted by three researchers using a data collection sheet. The results presented in this article are based on synthesis of the information collected from this evaluation.

# Analysis of the studies

Information collected from each article included: author(s) name(s); year and country of publication; the aim of the study; the main concepts under investigation; whether the concepts studied were defined (yes/no); the methods used (design, data collection and analysis); settings; sampling method; and response rate. Additionally, the research team considered whether ethical approval was reported (yes/no), how the validity and reliability of the study were reported, and, finally, they noted the main results. This information was entered on the data collection sheet and represents the data used for this review. During collection of this information the authors' original terms used in the articles were used; no interpretations about these were made. The validity of the review analysis was confirmed by: (1) using two researchers for the content analysis; and (2) by confirming the results and resolving possible problems within the research team.

#### Results

# Ethical concepts and contexts in clinical studies about caring for older people

The reviewed empirical studies focussed on several specific concepts. Those most frequently studied were patient autonomy, self-determination, informed consent, questions related to decision making, and ethical questions or dilemmas in various clinical care situations (e.g. feeding) (Table 1). 3-12,19-25,28-81

Most often, the study informants were health care professionals (n = 48), patients (n = 32), or relatives (n = 11). Two studies examined a sample of nursing students' perceptions of patient self-determination. <sup>37,54</sup> Some included several groups of informants. <sup>4,9,12,22,28,38,53,54,60,81</sup> Three studies focussed on nursing managers' perspectives on ethical values, dilemmas and decisions, <sup>31,69,81</sup> and two were about public and health care professionals' opinions about prioritization. <sup>75,76</sup>

Studies on ethical issues from older patients' point of view concentrated on concepts such as autonomy, self-determination, informed consent, privacy, integrity, abuse of older people, dependence, decision making, and truth telling. Other topics of common interest were ethically difficult situations, dilemmas or problems encountered in nursing care, and the use of technology in care.

The review revealed that health care workers seem to be virtuous, that is, concerned with doing right and good for their patients. <sup>7,8,55,56</sup> They try to develop good relationships with patients and their relatives. Typically, the studies concerned with professionals' point of view concentrated on ethically difficult situations and dilemmas in different health care settings, or on ethically problematic experiences of nurses. <sup>19-21,62</sup> Some studies focussed on topics such as abuse of older people, decision making, autonomy, physical restraints, integrity, moral activities, and perception of ethically problematic questions in care. <sup>6,22</sup>

Few of the empirical studies reviewed explored ethical challenges among older patients' relatives. Those available related to surrogate decision making and judgment when the decision maker was an impaired older patient. Studies in which public opinion was sought regarding ethical issues in health care in general were focussed on discussions about prioritization of care.

The studies on ethics in caring for older people were conducted in hospitals (n = 18), long-term care organizations (n = 16), nursing homes (n = 13), sheltered housing (n = 5), the community (n = 9), home care

 Table I. Ethical concepts, informants, settings, data collection and analysis methods of the studies reviewed

				Informants	nants						Set	Setting							Data	collect	Data collection method	ethod						Δ	Data analysis method	nalysi	s meth	por		
		Nurses	Patients Relatives	Relatives Students	noizezinegriO	Ranagers	Public	Educational facility	Home care or home	Sheltered housing	Community Outpatient clinic	Outpatient clinic	Long-term care institution	Hospital specialized care	Anivaing home	Hospice Semistructured interview	Semistructured interview Interview	Questionnaire	Semistructured questionnaire	Observation	Participant observation	Focus group	Техт дага	Clinical records	Literature review	Content analysis	Statistical analysis	Inductive analysis	Varrative analysis	Phenom. hermaneut. analysis	Grounded theory	Ethnographic analysis	Dialogic analysis	Concept analysis
Ethical concept	Reference																																	
Abuse of older people	Saveman et al., 1996 <sup>30</sup>	×							×					-			×													×				
	Bužgová and Ivanová, 2009 <sup>31</sup>	×	×			×								×	<del>                                     </del>		×													×				
Advocacy	Luke et al. 2008, <sup>32</sup>	×											×	,		×	<u> </u>									×								
Autonomy, patient	Randers and Mattiasson, 2004 <sup>33</sup>	×											×	,							×					×								
	Leino-Kilpi et al., 2003 <sup>4</sup> Scott et al., 2003 <sup>12</sup> Scott et al., 2003 <sup>29</sup>	×										×	J					×									×							
	Whitler, 1996 <sup>34</sup>	×												×			×														×			
	Hertz, 1996 <sup>35</sup>	×	×																				×											×
	High, 1990 <sup>36</sup>		×							^	×					×											×							
Self-determination	Válimäki et al., 2008³7			×								×	-					×									×							
	Hellström and Sarvimäki, 2007 <sup>24</sup>		×							×							×									×								
Dependence	Stabell et al., 2004 <sup>25</sup>		×											×						×							×	×						
Consent, informed consent	Leino-Kilpi et al., 2003 <sup>4</sup> Leino-Kilpi et al., 2003 <sup>9</sup> Schopp et al., 2003 <sup>11</sup>	×	×									×	-					×									×							
	Scott et al., 2003 <sup>29</sup>	×	×									×					×										×							
	Bravo et al., 2003 <sup>38</sup>		× ×	_						Ŷ	×							×									×							
Refusal	Mattiasson and Andersson, 1994 <sup>39</sup>	×												×				×								×								
Genetic testing	Skirton et al., 2006 <sup>40</sup>		×							^	×											×						×						

Table I (continued)

								ŀ						l	l	ſ			l			l	l			ŀ	l	l	l	l	l	l	l	l	Г
				lu	Informants	s						Setting	g						Δ	ata co	llectio	Data collection method	poq						Data	analy	Data analysis method	thod			
;	:	Nurses	Patients	Relatives	Students	noitszinsgrO	Managers Silding	Public Educational facility	Home care or home	Sheltered housing	Community	Outpatient clinic	Long-term care institution	Hospital specialized care	9mod gnisruM	Hospice	Semistructured interview	weiview	Questionnaire	Semistructured questionnaire	Observation	Participant observation	Focus group	Text data	Clinical records	Literature review  Content analysis	Statistical analysis		Inductive analysis	Narrative analysis	Phenom. hermaneut. analysis	Grounded theory	Ethnographic analysis	Dialogic analysis	Concept analysis
Ethical concept	Reference Change and Lional 200741	,			$\top$	+	+	+	+	-				;			,		$\top$			$\dashv$	+	+		;									-
Physical restraints	Chuang and Huang, 2007	×			1	+	+	+		4	_	_		×			×				+	-	+	-		×				-			_		
	Chien, 1999 <sup>42</sup>	×												×			×				×			^	×	×									
Truth telling	Costello, 2000 <sup>43</sup>		×											×				×			×										_	×			
Dignity	Ples chberger, 2007 <sup>44</sup>				Ĺ	×									×			×								×									l
	Jacelon et al., 2004 <sup>45</sup>		×								×												×		×	×									×
Integrity	Teeri et al., 2007 <sup>46</sup> Teeri et al., 2007 <sup>47</sup>	×		×									×						×								×								
	Randers and Mattiasson, 2004 <sup>33</sup>	×		×										×								×				×									
	Randers et al., 2002 <sup>48</sup>		×											×										×						×	v				
Right to touch	Routasalo and Isola, 1996 <sup>49</sup>	×	×										×				×									×									
Decision making: end of life	Schaffer, 2007 <sup>50</sup>	×	×	×				×	×					×	×	×	×									×									
	Elliot et al., 2009 <sup>51</sup>			×											×								×			×									
Decision making: patient involvement	Rotar-Pavlic et al., 2008 <sup>52</sup>		×									×					×									×									
Decision making: care discontinuation	Russ et al., 2007 <sup>53</sup>	×	×	×										×							×										^	×			
Ethical wills	Cohen-Mansfield et al., 2009 <sup>54</sup>		×		×										×			×													^	×			
Ethical decision making	Bolmsjö et al., 2006 <sup>55</sup>	×													×						×					×									
	Slettebo and Haugen Bunch, 2004 <sup>56</sup>	×													×			×			×										_	×			
	Kuuppelomäki and Lauri, 1991 <sup>8</sup>	×											×					×									×								
	Davidson et al., 1991 <sup>7</sup>	×												×				×									×								
	Vig et al., 2006 <sup>57</sup>			×					×								×									×									
	Kuuppelomäki, 1993 <sup>58</sup>	×													×				×								×								
Ethical discussion	Forsgärde et al., 2000 <sup>59</sup>	×								×									×								×								
							l	ĺ			ĺ											1	!	l						l					ì

Table I (continued)

				Infor	Informants						Ñ	Setting							Da	ita col	Data collection method	met.	poq					Data	Data analysis method	sis me	sthod		
Ethical concept	Reference	Nurses	Patients	Relatives	Szndenzs Organization	Мападега	- Public	Educational facility	Home care or home	Sheltered housing	Community	Outpatient clinic	Long-term care institution	Hospital specialized care	Aursing home	90iqzoH	Semistructured interview	weiview	Questionnaire	Semistructured questionnaire	Observation	Participant observation	Focus group	Text data	Clinical records Literature review	Content analysis	Statistical analysis	Inductive analysis	Narrative analysis	Phenom. hermaneut. analysis	Grounded theory	Ethnographic analysis	Dialogic analysis Concept analysis
Placement	Fjeltun et al., 2009 <sup>60</sup>	×	Ť	×	-	+					×		İ		T	1	1	×	1		-	+			-	×			-				_
Treatment choices	Zweibel and Cassel, 1989 <sup>61</sup>	1	×	1	-	-					Ĺ	×	Ĺ		L	1	1	×	1		-	1					×						
Ethical questions, issues	Haggström and Kihlgren, 2007 <sup>6</sup>	×	Ť.	×		-									×						1		×	,								Ĥ	×
	Enes and de Vries, 2004 <sup>5</sup>	×														×			Ĥ	×						×	×						
	Smith, 2005 <sup>3</sup>		×							×	×						×									×							
	Rees et al., 2009 <sup>62</sup>	×																							×	×							
Ethical challenges	Nordam et al., 2005 <sup>21</sup>	×												×				×											*	×			
Ethically difficult care situation	Nordberg et al., 1998 <sup>63</sup>	×											×					×										×					
Unethical behavior	O'Donoghue et al., 2004 <sup>64</sup>	×							×													Ŷ	×	v		×							
Moral actions	Randers and Mattiasson, 1999 <sup>65</sup>	×											×					×								×							
Feeding seriously ill people	Wilmot et al., 2002 <sup>66</sup>	×												×								_	×							*	×		
	Jansson et al., 1995 <sup>67</sup>	×												×				×											^	×			
Ethical standards	Elsner et al., 1999 <sup>23</sup>		×										×					×										×					
Discharge	Dill, 1995 <sup>68</sup>	×												×							×	J									×		
Ethically difficult situations, dilemmas	Nordam et al., 2005 <sup>21</sup>	×												×				×					×	,					*	×			
	Ehrenfeld et al., 1997 <sup>20</sup>	×	×											×				×															
	Elander et al., 1993 <sup>19</sup>	×											×					×								×							
	Dibelius, 2001 <sup>69</sup>					×					×		×					×								×							
	Sorlie et al., 2004 <sup>70</sup>	×												×				×											*	×			
Ethically problematic experiences	Teeri et al., 2006 <sup>22</sup>	×	×	×									×					×					×	J		×							
Moral orientation	Ellenchild Pinch and Parsons, 1997 <sup>71</sup>		×								×						×									×							
		1	1	1	1	1	-	-					]		1							1	-		_	-		-				3	4

Table I (continued)

	Concept analysis		ı —		ı	I		ı	ı	ı	ı	ı	1
	Dialogic analysis												
	Ethnographic analysis												
poq													
is me	Grounded theory												
Data analysis method	Phenom. hermaneut. analysis												
Data	Narrative analysis												
	Inductive analysis												
	Statistical analysis		×	×		×	×	×	×	×			
	Content analysis							×			×		×
	Literature review												
	Clinical records												
po	Text data												
meth	Focus group												×
ction	Participant observation												
Data collection method	Observation			×									
Data	Semistructured questionnaire												
	Questionnaire		×		×	×	×	×	×			×	
	Semistructured interview Interview									×	×	×	×
	Hospice												
	. Nursing home										×		
	Hospital specialized care			×									
ng gu	Long-term care institution								×	×			×
Setting	Outpatient clinic							×					
	Community					×							
	Sheltered housing		×		×								
	Home care or home											×	
	Educational facility						×						
	Public					×							
	Nanagers												×
ants	noizazinegrO												
Informants	Students												
=	Relatives												×
	Patients			×					×	×		×	×
	Nurses		×		×	×	×	×	×	×	×		×
		Keference	Juthberg et al., 2007 <sup>72</sup>	Irving, 2004 <sup>73</sup>	Juthberg and Sundin, 2009 <sup>74</sup>	Myllykangas et al., 1996 <sup>75</sup> Myllykangas et al., 2003 <sup>76</sup>	Wagner and Tabak, 1998 <sup>77</sup>	Barnes et al., 2002 <sup>78</sup>	Leino-Kilpi et al., 2003 <sup>4</sup> Leino-Kilpi et al., 2003 <sup>9</sup> Schopp et al., 2003 <sup>10</sup>	Scott et al., 2003 <sup>29</sup>	Sävenstedt et al., 2006 <sup>79</sup>	Blackhall et al., 1999 <sup>80</sup>	Dorsten et al., 2009 <sup>81</sup>
		Ethical concept	Perceptions of conscience		Experience of troubled conscience	Prioritization	Equality	Insurance, long-term care	Privacy		Use of technology		

Phenom. hermaneut., Phenomenological hermeneutic.

Table 2. Reliability and validity of the studies

Type of reliability or validity	No. of studies
Reliability	
Test-retest	2
Internal consistency; Cronbach's alpha coefficient	11
Item analysis	2
Inter-rater reliability; 2 observers/researchers	4
Validity	
Face	5
Content, use of expert panels/groups	7
Concept	5
Cultural sensitivity	7
Analysis, 2 or more researchers	20
Credibility	7
Transferability	5
Dependability	1
Conformity	1
Discussion about generalizability	8
Limitations section or paragraph included	16
Validity and reliability in general, or methodological considerations	6
Trustworthiness	2

(n = 5), and primary health care encounters or outpatient clinics (n = 2). Two studies were conducted in hospices.

The first study about ethics in care settings for older people appeared in the electronic databases in 1989. Most of the studies were conducted in Nordic countries: Sweden (n = 14), Finland (n = 8) and Norway (n = 6), USA (n = 16) and Canada (n = 1). Some were conducted in other parts of Europe, such as the UK (n = 6), Germany (n = 2), Ireland (n = 1), Czech Republic (n = 1) and Slovenia (n = 1). Others were conducted in Israel, Taiwan, China, Australia and South Africa (one from each country) and Japan (n = 2). There were also some international cross-cultural comparative studies (n = 8), in which up to seven countries participated.

## Methods used

The most common data collection tool used was various types of interview (n = 37) (Table 1). Numbers of interview informants ranged from one to 573 (mean 29). Unstructured interviews<sup>30,33</sup> included fewer informants than structured surveys.<sup>12</sup> Eighteen questionnaires were identified, which were associated with varying numbers of informants (35–887, mean 409). Two surveys focussed on multiple groups of informants, including the use of public opinion. Typically, these questionnaires were specifically developed for a particular study. None of the reviewed studies used systematically validated instruments for the measurement of ethical concepts in nursing care for older people.

Some of the studies (n=9) were conducted using observation as a data collection method. Numbers of observed cases/situations ranged from single activities to 256 patient situations (mean 53). Different types of textual data (narratives, vignettes and essays) were also used for studying ethical concepts. Three studies used focus groups (range: 2–8 groups, including up to 39 members). One concept analysis using the Walker and Avant method<sup>33</sup> was identified. One literature review about dignity was conducted. The information derived from this was confirmed using a focus group method. Another systematized review about nurses' perceptions of ethical issues was included.<sup>62</sup>

The most common method of analysis was content analysis of textual data (n = 49). Twenty-six of the studies used both descriptive and inferential statistics to examine associations between ethical concepts and the background variables of informants, and also to make between-group or between-country comparisons.

# Validity and reliability

In most of the studies, some description of and discussion about validity and/or reliability was identifiable (Table 2). However, the academic level of description and discussion was superficial and limited.

With reference to reliability, the most common form of test, used in 11 studies, was analysis of the internal consistency of the data collection instrument by using Cronbach's alpha coefficient. In some studies interrater reliability that improved by the use of several observers was mentioned.

Analysis of validity was more multidimensional. Two or more researchers were used to enhance validity of the content and/or classification of categories established in the analysis. Expert panels or groups were also used. In many studies, there was general discussion about study limitations, including some methodological considerations.

The ethical quality of the empirical studies was usually guaranteed by obtaining ethical approval to implement the study. In the reviewed articles, 38 of the reports (54%) included a mention about approval by an ethics or research committee, or there was a note about obtaining informed consent from the participants. This certainly depends on the development of research protocols and increased awareness of both ethical approval procedures and written informed consent among human research participants.

In general, however, validity of the research was not strongly evaluated or discussed. This is a clear limitation in these studies because they are empirical in nature and, thus, usability of the results is difficult to estimate in clinical practice.

#### Discussion

This review demonstrated that empirical research on ethics in nursing care for older people has received insufficient attention. Most of the reviewed empirical studies focussed on specific concepts, such as patient autonomy, self-determination, informed consent, integrity, and related concepts and individual clinical situations causing ethical dilemmas during decision making. These are important concepts in nursing ethics and this result may indicate that current research is concentrated around those that are the most important and central to the field.<sup>24</sup>

The reviewed studies were mainly descriptive and, although one research project (about autonomy, informed consent and privacy) had led to several publications, only one concept analysis and two literature reviews were found. Overall, the range of publications did not appear to be part of any ongoing coherent research program and seemed to be fragmented and multifaceted, focusing on selected specific issues arising in particular areas. This led the research team to believe that there were no strong research traditions in the area of ethics in nursing care for older people, which may be considered an indication of the academic immaturity of this research arena. However, authors focusing on research into ethics in this setting could be identified.

The informants taking part in the studies were most frequently nurses or older patients. However, a few studies focussed on older patients' relatives. Those researching nursing students' learning about professional ethics were rare. Workforce retirement projections<sup>16</sup> show that many nurses will retire in Organisation for Economic Co-operation and Development countries in the next few years. Because of this, expertise from the workforce may be lost and there is an urgent need for further research into how nursing students learn about ethical principles and how they apply this learning in their practice. This would help to develop the way nursing ethics is taught in continuing education programs.

Although a wide range of health care settings was covered by the studies identified, most focussed on institutional care. Research carried out, for example, in sheltered housing facilities, or at home, was poorly represented but seemed to increase since 2000. This is an important gap in the research profile of this area at a time when the older population<sup>13-15</sup> is increasing and there are strategic plans for reducing institutional care in favor of providing home care.<sup>82,83</sup> This is exemplified by the Disabled and Elderly Health Programs Group Strategic Action Plan<sup>82</sup> and the National Framework for High-Quality Services for Older People published by the Finnish Ministry of Social Affairs and Health.<sup>83</sup> These action plans discuss intentions to match the needs of the increasing older population with the facilities and resources required for this group. A mismatch between resources and facilities and the needs of older persons is in itself an ethical problem, and there is a dearth of empirical research on ensuring sound ethical decision making in this area. For example, from the results of the present review, ambulatory or outpatient clinics and how these cater for older people seem to be poorly studied. This is a concern because older people need and use health care services frequently, especially primary care services.<sup>84</sup> It seems that ethics in caring for older people is not a popular topic for ethics research. There may also be different opinions about the role of families and the welfare state.

The typical research methods used in the reviewed publications were interviews, survey questionnaires and observation, representing rather narrow methodological variation. The analytical methods used were many sided. Usually there was no discussion or conclusion about a suitable method, the study design, or the measurement instruments used. The studies were mainly descriptive, explorative, and cross-sectional. Only one study used a pre- and post-test design. The aim of the present review was to scope the need and areas for further study on ethics in caring for older persons. Although a solid and conceptual basis in the form of large research programs was not found, the descriptive studies noted in this review will provide guidance for some intervention studies, for example to investigate whether different educational interventions have an effect on patient autonomy or self-determination.

# Validity and limitations of the literature review

Some methodological issues need to be taken into account when interpreting the findings of this review. First, the literature search used only two electronic scientific databases. It has been found, however, that MED-LINE and CINAHL provide the highest number of references when using the search terms, including more references with a separate abstract. In addition, MEDLINE has been found to produce the most relevant references for search topics. 85 The overlap between the two databases was remarkable.

The search focussed on ethics in caring for older people and used the keywords: ethic\*, nursing or care or caring, and older or aged or older. This may have restricted the number of citations found as there might have been some relevant studies about specific concepts, such as autonomy and self-determination, that were missed in the search strategy. Searching MEDLINE and CINAHL did provide a wide range of articles and probably did cover the breadth of the research available. However, in order to be identified as nursing ethics research, should the abstract include 'nursing ethics'?

One limitation of the review is concerned with language. The search was limited to the English, Finnish, German and Swedish languages. There may have been some studies reported in other languages, which could have increased the number of articles identified. However, the search was conducted using a systematic search strategy followed by a four-stage analysis of the references to be included in the review. <sup>28</sup> The exclusion criteria were applied in the first three stages of the analysis by two researchers in phases one and two and three researchers in the third phase. The fourth phase of the analysis also included a third researcher, thus increasing the validity of the review process. Analysis of the studies included in the final sample was conducted by three researchers working independently. These separate analyses were then agreed with the rest of the research group, thus improving the validity of the findings.

Another limitation concerned the inclusion of empirical studies only. In ethics, important theoretical constructions and ideas are reported in theoretical studies, which may not provide empirical data. Our goal was, however, to concentrate on the empirical world of nursing science, <sup>28,86</sup> trying to find out about behaviors and actions in nursing practice. We therefore discarded any theoretical articles identified by the search. However, in the future, theoretical work could provide different information and perhaps a new perspective. There may also have been some useful empirical studies that were not captured by the search terms because their focus was on general health care; some of these would have included older people.

# Conclusions and implications for nursing research

The analysis of the reviewed literature revealed that research into ethics in nursing care for older people is multidimensional. No interpretations about concepts were made but the concepts found in the studies were used to provide an overview of the current research position within the aims of the scoping exercise. Overall, the empirical research on ethics in nursing care for older people seems to be fragmented, multifaceted and focussed on selected ethical concepts arising in particular areas rather than from a fundamental knowledge base from which continuous development can proceed.

This article opened by reviewing the state of knowledge and understanding on current worldwide ideas about ethics in older people's care in different health care settings. The findings of the study contribute to identifying gaps in nursing knowledge and understanding, so that improvement in the ethics of nursing care can continue in hospitals and long-term care institutions. The review may also assist nurse managers in the creation of a supportive practice environment. It is recommended that in-service training programs should include ethical issues and how to manage and cope with the feelings of uncertainty and ambiguity that arise in the ethically difficult situations that occur in everyday care health care situations with older patients.

Further research is needed to assist the development of a high standard of ethical nursing care to assist older patients in maintaining both their human and patient rights. This should be based on large collaborative research programs involving many research institutes. Research and practice development in this area is an important part of the role of nurses in hospital, long-term care and community settings as the need for an ethically competent workforce to care for older people builds up alongside the increase in older populations. These future studies should reduce the fragmentation of the current research base and take into account home care and sheltered housing as, over time, more older people will be cared for at home.

The question of what should be the proper role of the family and the welfare state in caring for people of advanced years should be addressed. As far as European values and norms for caring for older people are concerned, the moral responsibilities of the welfare state and levels of intergenerational solidarity are open to question.<sup>87</sup>

#### Conflict of interest statement

The authors declare that there is no conflict of interest.

#### References

\*Article included in the review.

- Bandman E, Bandman B. Nursing ethics through the life span, fourth edition. Upper Saddle River: Prentice Hall, 2002.
- 2. Thompson IE, Melia KM, Boyd KM, Horsburgh D. *Nursing ethics*, fifth edition. Edinburgh: Churchill Livingstone, 2007.
- 3. Smith KV. Ethical issues related to health care: the older adult's perspective. J Gerontol Nurs 2005; 31(2): 32–9.\*
- 4. Leino-Kilpi H, Välimäki M, Dassen T, et al. Perceptions of autonomy, privacy and informed consent in the care of elderly people in five European countries: general overview. *Nurs Ethics* 2003; 10: 18–27.\*

5. Enes SPD, de Vries K. A survey of ethical issues experienced by nurses caring for terminally ill elderly people. Nurs Ethics 2004; 11: 150–64.\*

- Haggström E, Kihlgren A. Experiences of caregivers and relatives in public nursing homes. Nurs Ethics 2007; 14: 691–701.\*
- 7. Davidson B, Vander Laan R, Davis A, et al. Ethical reasoning associated with the feeding of terminally ill elderly cancer patients: an international perspective. *Cancer Nurs* 1991; 13: 286–92.\*
- 8. Kuuppelomäki M, Lauri S. Dementiapotilaiden ja terminaalivaiheessa olevien iäkkäiden syöpäpotilaiden syöttämiseen liittyvä hoitotyön eettinen päätöksenteko eri maissa. (Ethical decision making of nurses associated with the feeding of patients with dementia and terminally ill elderly cancer patients in seven countries.) *Hoitotiede* 1991: 3: 146–53.\*
- 9. Leino-Kilpi H, Välimäki M, Dassen T, et al. Perceptions of autonomy, privacy and informed consent in the care of elderly people in five European countries: comparison and implications for the future. *Nurs Ethics* 2003; 10: 58–66.\*
- 10. Schopp A, Leino-Kilpi H, Välimäki M, et al. Perceptions of privacy in the care of elderly people in five European countries. *Nurs Ethics* 2003; 10: 39–47.\*
- 11. Schopp A, Välimäki M, Leino-Kilpi H, et al. Perceptions of informed consent in the care of elderly people in five European countries. *Nurs Ethics* 2003; 10: 48–57.\*
- 12. Scott PA, Välimäki M, Leino-Kilpi H, et al. Perceptions of autonomy in the care of elderly people in five European countries. *Nurs Ethics* 2003; 10: 28–38.\*
- 13. United Nations. *World population ageing*. Department of Economic and Social Affairs, Population Division. http://www.un.org/esa/population/publications/ageing/ageing2006.htm (2006, accessed December 2009).
- 14. European Union. *A new strategic approach to health for the EU (2008–2013)*. http://europa.eu/scadplus/leg/en/cha/c11579.htm (2008, accessed October 2008).
- 15. Sanderson W, Scherbov S. Rethinking age and ageing: a publication of the Population Reference Bureau. *Popul Bull* 2008; 63(4): 1–16. http://www.prb.org/pdf08/63.4aging.pdf (2008, accessed February 2009).
- 16. World Health Organization. *Working together for health*. The world health report 2006. WHO. http://www.who.int/whr/2006/whr06\_en.pdf (2006, accessed January 2009).
- 17. Organisation for Economic Co-operation and Development. *Long term care (LTC)*. http://www.oecd.org/document/61/0,3343,en\_2649\_33929\_35490493\_1\_1\_1\_1\_1,00.html (n.d., accessed December 2009).
- 18. Gordon M. Ethical challenges in end-of-life therapies in the elderly. Drugs Aging 2002; 19: 321-9.
- 19. Elander G, Drechsler K, Persson KW. Ethical dilemmas in long-term care settings: interviews with nurses in Sweden and England. *Int J Nurs Stud* 1993; 30: 91–7.\*
- 20. Ehrenfeld M, Tabak N, Bronner G, Bergman R. Ethical dilemmas concerning sexuality of elderly patients suffering from dementia. *Int J Nurs Pract* 1997; 3: 255–9.\*
- 21. Nordam A, Torjuul K, Sorlie V. Ethical challenges in the care of older people and risk of being burned out among male nurses. *J Clin Nurs* 2005; 14: 1248–56.\*
- 22. Teeri S, Leino-Kilpi H, Välimäki M. Long-term nursing care of elderly people: identifying ethically problematic experiences among patients, relatives and nurses in Finland. *Nurs Ethics* 2006; 13: 116–29.\*
- 23. Elsner RJ, Quinn ME, Fanning SD, Gueldner SH, Poon LW. Ethical and policy considerations for centenarians: the oldest old. *Image J Nurs Sch* 1999; 31: 263–7.\*
- 24. Hellstrom UW, Sarvimaki A. Experiences of self-determination by older persons living in sheltered housing. *Nurs Ethics* 2007; 14: 413–24.\*
- Stabell A, Eide H, Solheim GA, Solberg KN, Rustoen T. Nursing home residents' dependence and independence.
   J Clin Nurs 2004; 13: 677–86.\*
- 26. Raholm MB, Lindholm L. Being in the world of the suffering patient: a challenge to nursing ethics. *Nurs Ethics* 1999; 6: 528–39.

27. Suominen T, Savikko N, Kiviniemi K, Doran DI, Leino-Kilpi H. Work-empowerment as experienced by nurses in elderly care. J *Prof Nurs* 2008; 24(1): 42–5.

- 28. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Inform Libraries J* 2009; 26: 91–108.\*
- 29. Scott PA, Välimäki M, Leino-Kilpi H, et al. Autonomy, privacy and informed consent 3: elderly care perspective. Br J Nurs 2003; 12: 158–68.\*
- 30. Saveman BI, Hallberg IR, Norberg A. Narratives by district nurses about elder abuse within families. *Clin Nurs Res* 1996; 5: 220–36.\*
- 31. Bužgová R, Ivanová K. Elder abuse and mistreatment in residential settings. Nurs Ethics 2009; 16: 110-26.\*
- 32. Luke L, Redley M, Clare I, Holland A. Hospital clinicians' attitudes towards a statutory advocacy service for patients lacking mental capacity: implications for implementation. *J Health Serv Res Policy* 2008; 13(2): 73–8.\*
- 33. Randers I, Mattiasson AC. Autonomy and integrity: upholding older adult patients' dignity. *J Adv Nurs* 2004; 45: 63–71.\*
- 34. Whitler JM. Ethics of assisted autonomy in the nursing home: types of assisting among long-term care nurses. *Nurs Ethics* 1996; 3: 224–35.\*
- 35. Hertz JE. Conceptualization of perceived enactment of autonomy in the elderly. *Issues Ment Health Nurs* 1996; 17: 261–73.\*
- 36. High DM. Who will make health care decisions for me when I can't? J Aging Health 1990; 2: 291–309.\*
- 37. Välimäki M, Haapsaari H, Katajisto J, Suhonen R. Nursing students' perceptions of self-determination in elderly people. *Nurs Ethics* 2008; 15: 346–59.\*
- 38. Bravo G, Paquet M, Dubois MF. Knowledge of the legislation governing proxy consent to treatment and research. *J Med Ethics* 2003; 29: 44–50.\*
- 39. Mattiasson AC, Andersson L. Staff attitude and experience in dealing with rational nursing home patients who refuse to eat and drink. *J Adv Nurs* 1994; 20: 822–7.\*
- 40. Skirton H, Frazier LQ, Calvin AO, Cohen MZ. A legacy for the children: attitudes of older adults in the United Kingdom to genetic testing. *J Clin Nurs* 2006; 15: 565–73.\*
- 41. Chuang YH, Huang HT. Nurses' feelings and thoughts about using physical restraints on hospitalized older patients. *J Clin Nurs* 2007; 16: 486–94.\*
- 42. Chien WT. The use of physical restraints to psychogeriatric patients in Hong Kong. *Issues Ment Health Nurs* 1999; 20: 571–86.\*
- 43. Costello J. Truth telling and the dying patient: a conspiracy of silence? Int J Palliat Nurs 2000; 6: 398-405.\*
- 44. Pleschberger S. Dignity and the challenge of dying in nursing homes: the residents' view. *Age Aging* 2007; 36: 197–202.\*
- 45. Jacelon CS, Connelly TW, Brown R, Proulx K, Vo T. A concept analysis of dignity for older adults. *J Adv Nurs* 2004; 48: 76–83.\*
- 46. Teeri S, Välimäki M, Katajisto J, Leino-Kilpi H. Maintaining the integrity of older patients in long-term institutions: relatives' perceptions. *J Clin Nurs* 2007; 16: 918–27.\*
- 47. Teeri S, Välimäki M, Katajisto J, Leino-Kilpi H. Nurses' perceptions of older patients' integrity in long-term institutions. *Scand J Caring Sci* 2007; 21: 490–9.\*
- 48. Randers I, Olson TH, Mattiasson A-C. Confirming older adult patients' views of who they are and would like to be. *Nurs Ethics* 2002; 9: 416–31.\*
- 49. Routasalo P, Isola A. The right to touch and be touched. Nurs Ethics 1996; 3: 165-76.\*
- 50. Schaffer MA. Ethical problems in end-of-life decisions for elderly Norwegians. Nurs Ethics 2007; 14: 242-57.\*
- 51. Elliot BA, Gessert CE, Peden-McAlpine C. Family decision-making in advanced dementia: narrative and ethics. Scand J Caring Sci 2009; 23: 251–8.\*
- 52. Rotar-Pavlic D, Svab I, Wetzels R. How do older patients and their GPs evaluate shared decision-making in health-care? *BMC Geriatr* 2008; 8:9.\*

53. Russ AJ, Shim JK, Kaufman SR. The value of 'life at any cost': talk about stopping kidney dialysis. *Soc Sci Med* 2007; 64: 2236–47.\*

- 54. Cohen-Mansfield J, Regier NG, Peyser H, Stanton J. Wisdom of generations: a pilot study of the values transmitted in ethical wills of nursing home residents and student volunteers. *Gerontologist* 2009; 49: 525–35.\*
- 55. Bolmsjö IA, Sandman L, Andersson E. Everyday ethics in the care of elderly people. *Nurs Ethics* 2006; 13: 249–63.\*
- 56. Slettebo A, Haugen Bunch E. Ethics in nursing homes: experience and casuistry. *Int J Nurs Pract* 2004; 10: 159–65.\*
- 57. Vig EK, Taylor JS, Starks H, Hopley EK, Fryer-Edwards K. Beyond substituted judgment: how surrogates navigate end-of-life decision-making. *J Am Geriatr Soc* 2006; 54: 1688–93.\*
- 58. Kuuppelomäki M. Ethical decision making on starting terminal care in different health-care units. *J Adv Nurs* 1993; 18: 276–80.\*
- 59. Forsgärde M, Westman B, Nygren L. Ethical discussion groups as an intervention to improve the climate in interprofessional work with the elderly and disabled. *J Interprof Care* 2000; 14: 351–61.\*
- 60. Fjelltun AM, Henriksen N, Norberg A, Gilje F, Normann HK. Carers' and nurses' appraisals of needs of nursing home placement for frail older in Norway. *J Clin Nurs* 2009; 18: 3079–88. Epub 2009 Apr 3.\*
- 61. Zweibel NR, Cassel CK. Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. *Gerontologist* 1989; 29: 615–21.\*
- 62. Rees J, King L, Schmitz K. Nurses' perceptions of ethical issues in the care of older people. *Nurs Ethics* 2009; 16: 436–52.\*
- 63. Nordberg A, Udén G, Andrén S. Physicians', registered nurses' and enrolled nurses' stories about ethically difficult episodes in the care of older patients. *Eur Nurs* 1998; 3: 3–13.\*
- 64. O'Donoghue K, Jooste K, Botes A. Guidelines for the management of unethical behaviour in homes for older persons. Health SA Gesondheid 2004; 9: 79–89.\*
- 65. Randers I, Mattiasson A. The Aristotelian ethics: grounds for understanding moral actions of experienced registered nurses in the care of elderly individuals. *Nordic J Nurs Res Clin Stud (Vård i Norden)* 1999; 19(1): 18–23.\*
- 66. Wilmot S, Legg L, Barratt J. Ethical issues in the feeding of patients suffering from dementia: a focus group study of hospital staff responses to conflicting principles. *Nurs Ethics* 2002; 9: 599–611.\*
- 67. Jansson L, Norberg A, Sandman PO, Åström G. When the severely ill elderly patient refuses food. Ethical reasoning among nurses. *Int J Nurs Stud* 1995; 32: 68–78.\*
- 68. Dill AE. The ethics of discharge planning for older adults: an ethnographic analysis. *Soc Sci Med* 1995; 41: 1289–99.\*
- 69. Dibelius O. Pflegemanagement im spannungsfeld zwischen ethik und ökonomie: eine qualitative untersuchung in der stationären und teilstationären altenpflege. (Nursing management in conflict between ethics and economy: a qualitative study in institutional and semi community care of older people.) *Pflege* 2001; 14: 407–13 (in German).\*
- Sørlie V, Kihlgren AL, Kihlgren M. Meeting ethical challenges in acute care work as narrated by enrolled nurses. *Nurs Ethics* 2004; 11: 179–88.\*
- 71. Ellenfield Pinch WJ, Parsons ME. Moral orientation of elderly persons: considering ethical dilemmas in health care. *Nurs Ethics* 1997; 4: 380–93.\*
- 72. Juthberg C, Eriksson S, Norberg A, et al. Perceptions of conscience in relation to stress of conscience. *Nurs Ethics* 2007; 14: 329–43.\*
- 73. Irving K. Inappropriate restraint practices in Australian teaching hospitals. Aust J Adv Nurs 2004; 21: 23–7.\*
- 74. Juthberg C, Sundin K. Registered nurses' and nurse assistants' lived experience of troubled conscience in their work in elderly care: a phenomenological hermeneutic study. *Int J Nurs Stud* 2009; 47: 20–9. Epub 2009 Jul 1.\*
- 75. Myllykangas M, Ryynänen OP, Kinnunen J, Takala J. Comparison of doctors', nurses', politicians' and public attitudes to health care priorities. *J Health Serv Res Policy* 1996; 1: 212–6.\*

76. Myllykangas M, Ryynänen OP, Lammintakanen J, et al. Clinical management and prioritization criteria: Finnish experiences. *J Health Organ Manag* 2003; 17: 338–48.\*

- 77. Wagner N, Tabak N. The old get equal care: myth or reality? Int J Nurs Pract 1998; 4: 234-9.\*
- 78. Barnes LE, Asahara K, Davis AJ, Konishi E. Questions of distributive justice: public health nurses' perceptions of long-term care insurance for elderly Japanese people. *Nurs Ethics* 2002; 9: 67–79.\*
- 79. Sävenstedt S, Sandman PO, Zingmark K. The duality in using information and communication technology in elder care. *J Adv Nurs* 2006; 56: 17–25.\*
- 80. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. *Soc Sci Med* 1999; 48: 1779–89.\*
- Dorsten AM, Sifford KS, Bharucha A, Mecca LP, Wactlar H. Ethical perspectives on emerging assistive technologies: insights from focus groups with stakeholders in long-term care facilities. *J Empir Res Hum Res Ethics* 2009; 4: 25–36.\*
- 82. DEHPG. 2007–2009 Strategic Action Plan. Disabled and Elderly Health Programs Group. http://www.cms.hhs.gov/NewFreedomInitiative/downloads/DEHPG%20Strategic%20Plan%202007.pdf (2007, accessed March 2009).
- 83. Ministry of Social Affairs and Health. *National framework for high-quality services for older people*. (Ministry of Social Affairs and Health publications 2008:5.) Helsinki: Edita, 2008.
- 84. World Health Organization. *Towards age-friendly primary health care*. http://whqlibdoc.who.int/publications/2004/9241492184.pdf (2004, accessed March 2009).
- 85. Subirana M, Solá I, Garcia JM, Gich I, Urrútia G. A nursing qualitative systematic review required MEDLINE and CINAHL for study identification. *J Clin Epidemiol* 2005; 58: 20–5.
- 86. Zander PE. Ways of knowing in nursing: the historical evolution of a concept. *J Theor Construct Test* 2007; 11(1): 7–11.
- 87. Daatland SO, Herlofson K. 'Lost solidarity' or'changed solidarity': a comparative European view of normative family solidarity. *Ageing Soc* 2003; 23: 537–60.