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How do journals publishing palliative and end-of-life care research report ethical approval and informed consent?

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Abstract: This study explores how papers published in international journals in palliative and end-of-life care report ethical approval and informed consent. A literature search following PRISMA guidelines was conducted in PubMed, the Web of Science Core Collection, Scopus, the ProQuest Social Science Premium Collection, PsycINFO, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL). A total of 169 empirical studies from 101 journals were deductively coded and analysed. The results showed that 5% of publications provided no information on ethical approval, 12% reported minimal information, 56% reported rudimentary information, and 27% reported comprehensive details. We also found that 13% did not report any information on informed consent, 17% reported minimal information, 50% reported rudimentary information, and 19% reported comprehensive details. The prevalence of missing and incomplete ethical statements and inadequate reporting of informed consent processes in recent publications raises concerns and highlights the need for improvement. We suggest that journals advocate high reporting standards and potentially reject papers that do not meet ethical requirements, as this is the quickest path to improvement.

Keywords: bioethics, ethical approval, informed consent, palliative care, palliative medicine, research ethics, systematic review

INTRODUCTION

When publishing research, it is customary to address possible ethical issues or aspects through ethical statements or declarations. These include statements about gaining ethical approval or whether a waiver was applicable, clinical trial registration, compliance with ethical guidelines such as the Helsinki Declaration (WMA, 2013) or Good Clinical Practice, confidentiality measures, compliance with data protection regulations, possible conflicts of interest, authorship responsibility, article originality, and the informed consent process. Such statements can be part of the methods section or added as separate entries. The idea behind this practice is to assure the reader that the research is in accordance with ethical and legal requirements.

Publishers often place particular emphasis on ethical vetting and informed consent, as exemplified by SAGE: 'The inclusion of ethics approval and informed consent statements is a fundamental requirement for research articles and a key responsibility for each handling Editor to uphold' (SAGE, n.d.). This is in line with guidance from the Committee on Publication Ethics (COPE): COPE's Core Practices also specify the need for editors to maintain ethical oversight of published research. If appropriate to the subject areas covered by your journal, you might also need to establish policies and procedures to address: Details of ethical approval and informed consent for studies in humans (COPE, 2019). Reporting guidelines likewise incorporate these obligations; as, for example, the Standards for Reporting Qualitative Research, which hold that an article should include 'Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof' (O'Brien et al., 2014). Thus, if ethical approval is not needed due to regulations or because an appropriate authority has granted an exemption, publishers typically ask for this to 'be stated within the manuscript with a full explanation. Where a study has been granted an exemption, the name of the ethics committee which provided this should also be included' (Dovepress, 2022). Medical journals in this regard often refer to the recommendations of the International Committee of Medical Journal Editors, which stresses this obligation (ICMJE, 2022). Regarding informed consent, journals following the ICMJE guidelines are expected to ask that these statements include information on whether consent was written, and if not, why; whether approval has been granted for doing the research without consent; and how consent for the inclusion of, for example, children and adolescents was handled. In this respect, journals function as important factors in ensuring that ethical requirements are met.

Differences in reporting ethical approval and informed consent have been studied previously. A review of medical research publications reported that 31% did not describe whether informed consent and ethical approval were obtained (Schroter et al., 2006). Another review, one of otolaryngology research journals, showed that 49.9% of the publications lacked a statement of ethical approval and 42.9% lacked disclosure of informed consent; moreover, a lack of ethical approval statement was associated with a lack of informed consent disclosure (Murphy et al., 2015). A retrospective observational study of nursing research found that 87.5% of publications reported informed consent (Wu et al., 2019), and a study of paediatric surgical research showed that 16% of the publications reported informed consent and 54% reported ethical approval (Dingemann et al., 2011). Reporting of ethical approval was low (20%–23%) from 2010 to 2012, then increased steadily to 49% in 2019. More recently, a study on ten nursing and two paediatric journals between 2015 and 2019 found that 87.9% of articles reported ethical approval, with prospective studies showing higher rates than retrospective studies. Slightly more than half of the articles reported written informed consent and child consent (assent) were reported in 6.3–29.6% of cases (Wu et al., 2021). A recent study on health and social sciences research in Sweden found a failure to report ethical approval in 6% of publications with somatic focus, 11% with non-somatic focus, and 27% in social sciences. Interventional studies reported ethical approval and informed consent more often than observational studies (Asplund & Hulter Asberg, 2021).

Key points

- In scientific publishing of empirical research on humans, it is expected that statements on ethical approval and informed consent from participants accompany the article.
- A total of 169 empirical papers from 101 journals in palliative and end-of-life care were analysed to determine journal adherence to standards for ethical statements.
- Regarding ethical approval, 5% of the papers provided no information, 12% reported minimal, 56% reported rudimentary, and 27% reported comprehensive details.
- Concerning informed consent, 13% of the papers failed to report, 17% reported minimal, 50% reported rudimentary, and 19% reported comprehensive details.
- Journals should advocate for reporting standards and potentially reject papers not meeting them, as this approach could expedite improvement.

According to the Declaration of Helsinki, patients should receive specifically considered protection in research (WMA, 2013). One patient group that may be particularly vulnerable is patients receiving palliative care (specialized medical care for people living with a serious illness) or end-of-life care (comfort care after one has decided to forgo curative treatments). These patients are seriously ill and/or dying and have to cope with their illness or treatment giving side effects, pain, distressing symptoms, stress, and existential issues. Asking them about participation in research is quite delicate and there is a risk that participants may place a disproportionate portion of trust and hope in researchers and research (Alexander, 2010; Godskesen et al., 2013). This group could experience several vulnerabilities; ranging from decisional incapacity and giving involuntary consent due to lack of treatment options, to undue susceptibility to harm due to frailty or organ dysfunction. Researchers should therefore take extra precautions and follow a rigorous ethical approach: obtaining ethical approval, ensuring that high-quality information is provided to participants, making sure that any decision to consent or refuse to participate in research is voluntary, specific, and explicit, and that all of this is documented in research publications (Hurst, 2008; Phipps, 2002). This complies with the research ethics responsibility of every researcher to continuously reflect on ethical aspects in their work to ensure that the work is both of good quality and morally acceptable.

AIM

The aim of this study was to explore the level of compliance with standards for including statements on ethical approval and informed consent in international journals that report on palliative and end-of-life care research. The specific research questions were:

1. How do journals publishing original palliative or end-of-life care research report ethical approval or its absence?
2. How do journals publishing original palliative or end-of-life care research report on the informed consent process?

METHODS

Answering the research questions required two methodological steps: first, identifying relevant publications by applying methodological approaches used in systematic reviews for collecting relevant papers; and second, evaluating the publications' content to gauge how the journals comply with demands for the reporting of ethical approval and informed consent. The approach incorporated document analysis with deductive codes. More details of the steps are given below.

The present study differed from a systematic review in that we sought to evaluate the use of ethical approval and informed consent statements rather than to synthesize scientific evidence about a specific issue. However, since the intention was to collect all publications within specific parameters, methodological approaches for systematic reviews were considered suitable. Strech *et al*. recommend that methodology, issue, and participants are included as parameters when developing a review in empirical bioethics (Strech et al., 2008). As this review included questions related to research ethics, we used these three components when identifying relevant articles: methodology (i.e., quantitative, qualitative, mixed methods, or case reports), issue (i.e., palliative or end-of-life care research), and participants (i.e., patients or their family members). The search string included synonyms in English and the Scandinavian languages with truncation and Medical Subject Heading terms and was applied to all fields. A filter was used to restrict the results to articles published after 1 January 2019; this short and recent period was chosen to capture the present state of ethical approval and informed consent reporting in the fields studied. A professional medical librarian performed the search on 30 March 2022. The identified publications were exported and collated in EndNote (Clarivate™) to remove duplicates.

The inclusion criteria were (a) end-of-life or palliative care in Norway and Sweden; (b) original and peer-reviewed articles; (c) Scandinavian or English language; and (d) empirical findings. Exclusion criteria were (*a**) populations outside end-of-life or palliative care in Norway and Sweden, (*b**) studies on health care personnel, (*c**) studies based on registers or entirely anonymised data, and (*d**) papers in the 'grey literature' (e.g., conference abstracts, thesis, editorials, letters or comments, perspectives, opinion pieces) as well as reviews.

The following search terms were used: 'original research', 'end of life care', 'palliative care', 'Norway', and 'Sweden'. To cover a wide range of medical, psychological, social, and nursing science sources, the following databases were searched for indexed empirical studies: PubMed, the Web of Science Core Collection, Scopus, the ProQuest Social Sciences Premium Collection, PsycINFO, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL).

The original search strategy was designed for PubMed and reviewed internally by Uppsala University Library librarians. To further validate the search strategy, an external review was carried out by a medical librarian at Karolinska Institutet University Library. The review included examining the choice of search terms, subject terms, and the overall structure of the search strategy, including how well it corresponded with the research questions. After the internal and external reviewers had been given the opportunity to provide feedback, the strategy was updated according to their suggestions before being modified for the remaining databases. The goal was to make the searches as identical as possible in the different databases in order to gain results from similar starting points regardless of platform. The searches are fully described in the Appendix.

The screening process was performed in Rayyan, a software application developed to facilitate systematic collaborative reviews (Ouzzani et al., 2016). Duplicates were removed, and two researchers screened titles and abstracts independently and in duplicate (T.G. and S.E.). Conflicting judgements were discussed until consensus was reached. Subsequently, all remaining references, including abstracts, were transferred to an Excel sheet and all potentially relevant publications were screened (T.G., S.E., K.J.V., W.B., G.H., and B.H.) to identify articles to be downloaded in full. Publications that did not meet the inclusion criteria were excluded. Discrepancies and doubts regarding the relevance of publications downloaded in full were solved by discussion and consensus among two authors (T.G. and S.E.). Once consensus was reached on which publications to include, a standardized form based on the inclusion and exclusion criteria and previous studies was used to extract data (T.G., S.E., K.J.V., W.B., B.H., and G.H.).

For the extraction and synthesis, we treated the publications as documents and approached them using *document analysis* as a method (Asdal & Reinertsen, 2021) by coding them using deductive codes (Matthew et al., 2018). The following information was extracted from each of the publications: (1) identification of the study (article title; publication year; journal; country of the study); (2) methods used (quantitative, qualitative, mixed methods, case study); (3) reporting of ethical approval; and (4) description of the informed consent process.

Compliance with ethical standards requires the inclusion of clear and comprehensive ethics statements with a clear and concise ethical approval/informed consent statement covering all relevant information. The extracted ethical approval and informed consent statements were coded using a variant of a scoring

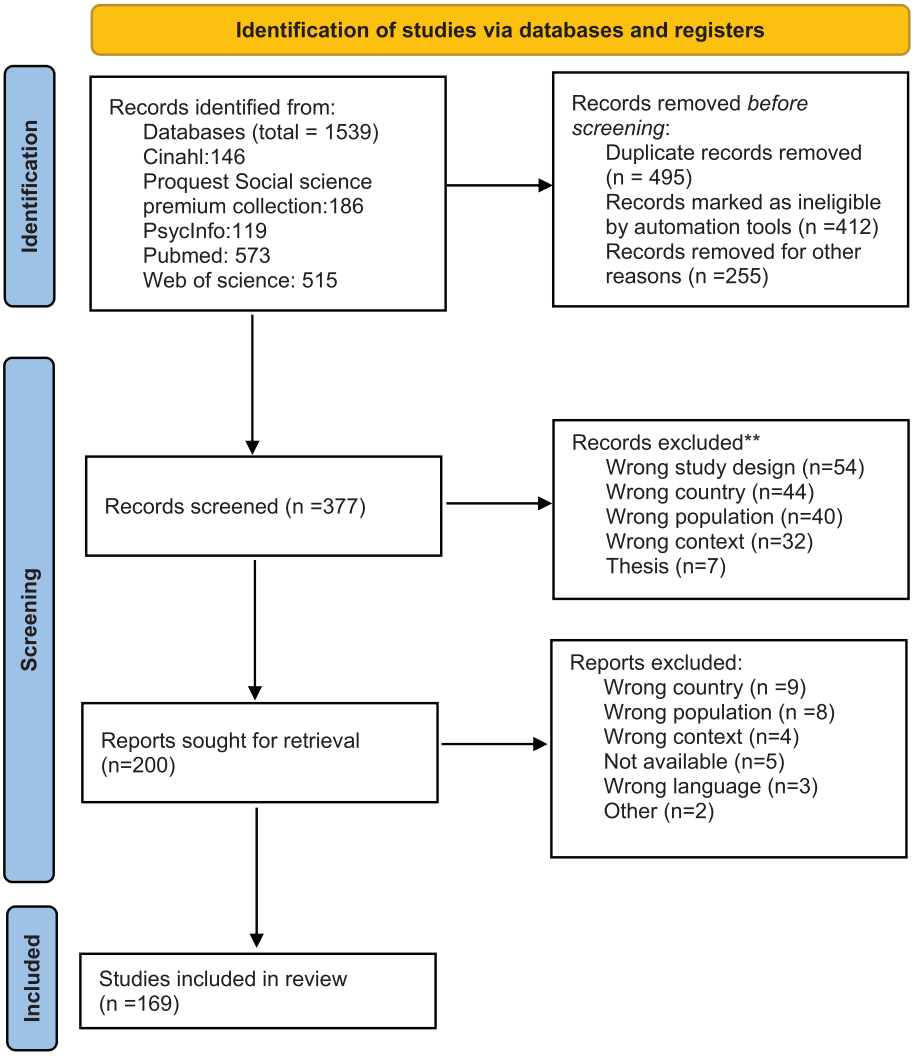

FIGURE 1 PRISMA 2020 flow diagram for included searches of databases.

scheme developed by Laothavorn *et al*. (2019). We expanded on their approach in that we split their highest score into two levels (scores 2 and 3, as described below) in order to differentiate between publications that reported some relevant details and publications that gave all relevant information. We also expanded the description of the scores with more detail regarding what kind of information should be included in ethical approval and informed consent statements to live up to what we believe should constitute 'best practice' and ensure consistency in the coding. Our familiarity with ethical review regulations and practices in Sweden and Norway made it possible for us to judge the extent to which the ethical statements met the expected standard; for example, if it is clear that the proper national authority has vetted the project (both Norway and Sweden has a legally appointed authority for ethical vetting). Each article was given one score for the ethical approval statement and one for the informed consent statement, with each score ranging from 0 to 3 based on the following criteria:

0: No reference to ethical approval/informed consent.

1: Minimal reference to ethical approval/informed consent (e.g., 'Ethical approval was granted', 'Informed consent was obtained').

2: A rudimentary but clear and concise ethical approval/informed consent statement including *one* piece of detailed information (as defined below).

3: A clear and concise ethical approval/informed consent statement including all relevant information in detail. Regarding ethical approval, this detailed information included the identity of the board, committee, or authority who granted the ethical approval or waiver, the identification number of the decision, or the act under which the decision was taken. Regarding informed consent, relevant details included what type of consent was obtained, from whom, the act under which the process fell, and a fuller description of the informed consent process.

The articles were distributed among the co-authors for scoring. Discrepancies were resolved either by discussion or, where there was lack of agreement, by the first author (T.G.). The first author also double-checked all extracted data by comparing them with the original publications.

RESULTS

The electronic searches yielded 1539 records; after removing duplicates and ineligible records, the remaining 377 records were screened. Assessment of titles and abstracts based on the inclusion criteria resulted in 200 records remaining. The full texts of all these articles were obtained, and after applying the inclusion criteria to these, 31 additional records were excluded. As such, 169 studies met the inclusion criteria and were included in the review (see PRISMA Fig. 1).

Sample

The 169 studies were published in 101 different journals, in 2020 ($n = 60$, 36%), followed by 2019 ($n = 58$, 34%), 2021 ($n = 38$, 22%), and 2022 (up to 30 March 2022: $n = 13$, 8%; Table 1). The most common study design comprised quantitative, observational, or interventional studies ($n = 114$, 67%), followed by qualitative interview studies ($n = 38$, 22%), mixed-methods studies ($n = 10$, 6%), and case studies ($n = 7$, 4%). Study participants were most commonly patients only ($n = 127$, 75%), followed by family members only ($n = 27$, 16%) and patients with family members ($n = 15$, 9%).

Reporting of ethical approval

Ethical approval was not reported in 5% (9/169) of the publications (Table 2). Articles reporting only minimal information about ethical approval (e.g., 'Ethical approval was granted') comprised 12% (20/169) of the publications. More than half of the publications (95/169, 56%) included a rudimentary report of ethical approval; that is, a declaration of ethical approval along with limited details such as the identity of the board, committee, or authority who granted the ethical approval or waiver, or the identification number of the decision. Finally, 27% (45/169) of the publications included all relevant information in their report on ethical approval.

TABLE 1 Characteristics of the studies included in this review: participants, methods used, year published, and country.

	$n = 169$ *n* (%)
Participants	
• Patients only	127 (75)
• Patients and family members	15 (9)
• Family members only	27 (16)
Study design	
• Quantitative, observational, or interventional	114 (67)
• Qualitative	38 (22)
• Mixed methods	10 (6)
• Case studies	7 (4)
Year published	
• 2022	13 (8)
• 2021	38 (22)
• 2020	60 (36)
• 2019	58 (34)

Reporting informed consent

Informed consent was not reported in 13% (23/169) of the publications. Articles reporting only minimal information about informed consent (e.g., 'Informed consent was obtained') comprised 17% (29/169) of the publications. More than half of the publications (85/169, 51%) included a rudimentary report of informed consent; that is, a consent statement along with limited details such as the type of consent obtained, from whom it was obtained, or some description of the process. Finally, 19% (32/169) of the publications described the informed consent process comprehensively by including a clear and concise informed consent statement with information about what type of consent was obtained, from whom it was obtained, the act under which the process fell, and a fuller description of the informed consent process.

DISCUSSION

The present results show that many articles published on palliative and end-of-life research from the last couple of years did not include comprehensive reports of ethical approval or the informed consent process. Overall, 5% failed to report any information about ethical approval, 12% reported minimally, 56% reported rudimentarily, and 27% had a clear and comprehensive report on ethical approval. Concerning informed consent, 13% failed to report any information, 17% reported minimally, 50% reported rudimentarily, and only 19% reported the informed consent process comprehensively. Full compliance with ethical standards requires the inclusion of a clear and comprehensive ethics statement along with a clear and concise ethical approval/informed consent statement covering all relevant information,

TABLE 2 Ethical approval and informed consent scores from 0 to 3, corresponding to missing, minimal, rudimentary, and comprehensive statements.

	Ethical approval ($n = 169$)	Informed consent ($n = 169$)
Score	Total group *n* (%)	Total group *n* (%)
3 (comprehensive)	45 (27)	32 (19)
2 (rudimentary)	95 (56)	85 (51)
1 (minimal)	20 (12)	29 (17)
0 (missing)	9 (5)	23 (13)
	169 (100)	169 (100)

and this was required to achieve the highest score in our coding (see Box 1 for an example of a comprehensively described ethical approval and informed consent according to score 3). Our results show that most articles fail in this ambition. Thus, the journal editors and researchers behind these publications are underperforming in observing the ethical demands placed upon them.

The lack of adequate ethical approval and informed consent statements in the examined publications does not imply that the research lacked ethical rigour. Nevertheless, a failure to report properly ethical approval and informed consent can lead the reader to question whether the researchers conducted the work with sufficient ethical awareness and can lead to a decreased trust in the work. The lack of transparency also makes it challenging to identify possible deviations from good research practice. While this is important in any type of research that involves human subjects, it is especially so in research that involves vulnerable patient groups. One implication of our results is that researchers perhaps underestimate the importance of disclosing information about how they handle vulnerable patients, as is evident in palliative care. Such non-disclosure is a notable breach of ethical standards, which link vulnerability to an obligation to provide 'specifically considered protection' (WMA, 2013). In this, the journals examined functioned poorly in their role of gatekeepers and guarantors.

Our results are congruent with previous studies. A recent study by Asplund and Hulter Asberg (2021) found that health and social sciences research in Sweden failed to report ethical review in 6% of publications with somatic focus, 11% with non-somatic focus, and 27% in social sciences. A study by Bonsu *et al.* (2022) examined the reporting of ethical approval and informed consent in research utilizing human or animal subjects published in six forensic science journals. They found that just over a third of all the publications stated that the authors had obtained ethical approval, and a majority of these reported the name of the ethical committee, but only a third provided an approval code. Informed consent processes were reported in 527 (17.5%) studies, but only 155 reported that written informed consent was obtained, and 11 reported obtaining oral consent; the remaining 357 studies (67.7%) did not report the process used to gain consent. Taken together, results like these and ours suggest a low level of proper declarations of ethical approval and informed consent within the investigated disciplines. This situation requires urgent rectification. Laothavorn *et al.* (2019) found that journals from Asian countries often reported ethical approval adequately, but many failed to report informed consent. Not surprisingly, they also found a significant relationship between ethical approval/informed consent statement scores and journals' instructions: better ethical approval and informed consent instructions from journals corresponded to a higher percentage of articles including adequate reports of ethical approval/informed consent.

We therefore suggest that journals should strongly advocate for the importance of reporting ethical approval and informed consent by strictly enforcing high standards for ethical approval and informed consent reporting. This can be achieved by adopting the guidelines proposed by COPE and rejecting publications that fail to comply, particularly in cases involving vulnerable individuals at the end of life. One way to implement this is by making the submission of these statements a requirement for acceptance or as a criterion for considering a submission complete. Such measures would ensure that the journal acquires the necessary information.

Here, the power lies with the journals that accept or reject the articles. Therefore, a faster and more efficient change can be achieved by encouraging journals to seek standardized ways of reporting ethical approval and informed consent. Further education of researchers about the significance of research ethics and transparent research practices is also important. From a long-term perspective, it is paramount for research training to place

BOX 1 A comprehensively described ethical approval and informed consent according to score 3.

'The KUPA project was approved by the Regional Ethics Review Board in Lund, Sweden (reference number: 2015/4). The study was guided by ethical principles for medical research in accordance with the ethical standards of the Declaration of Helsinki [32], and conducted in accordance with the Swedish Ethical Review of Research Involving Humans Act [33] and the General Data Protection Regulation [GDPR] [34].	Ethical approval
Prior to the interviews and before the participants sign the written consent form, the participants were given verbal and written information about the study. Written consent was obtained from participants. Participation was voluntary and could be interrupted at any time without the participants having to give a reason and without any consequences. Since the sample consisted of a vulnerable group i.e. frail older persons various efforts were made to minimize the risk of unintentional harm. First, the selection of older persons was made based upon the contact person's knowledge of the older person and his/her ability to manage an interview lasting for about 1 h. Second, the researchers were observant if the older person got tired during the interview and offered to interrupt the interview and come back another day. Third, the researchers were also observant to signs of depressed mood or anxiety during the interview, and in those cases immediately contacted the older persons' contact person at the nursing home, who in turn could ask for counselling from nurses or physicians. Fourth, weekly meetings were held during the data collection period within the research group, led by the experienced project manager. Difficulties identified in an interview situation were discussed and managed from the ethic principle of non-maleficence. Furthermore, to maintain the principle of non-maleficence, the participants were guaranteed confidentiality i.e. the collected data were encoded so that individuals could not be identified. Only the codes were used during the analysis, and the findings were reported at a group level. The code lists were stored in locked cabinets apart from the interviews. To create an environment as beneficial as possible for the participants, the participants themselves chose the time and place for the interviews'.	Informed consent

Note: Ref.: Tjernberg J. & Bökberg C. Older persons' thoughts about death and dying and their experiences of care in end-of-life: A qualitative study. *BMC Nurs*. 2020 Dec 16;19(1):123. doi: 10.1186/s12912-020-00514-x.

emphasis on these issues and emphasize author responsibility. While the COPE guidelines may lack specificity regarding the details they require, we suggest that our score number three, which outlines comprehensive statement requirements, could be valuable. Furthermore, journals should also request that authors specify the measures taken to ensure special protection for participants due to their vulnerability.

The top evaluation score (i.e., 3) in our exploration of compliance with standards for including statements on ethical approval and informed consent requires that important information about these matters is provided. We are seeking clear and concise statements that provide relevant and detailed information about these aspects. For ethical approval, it is important to disclose the identity of the review board. This allows for potential contact with them for verification or inquiries, and assures the readers that the research complies with national policies and follows the principles of the Helsinki Declaration, of which ethical review boards are the guarantors (Wu et al., 2019). Additionally, providing the identification number of the approval decision is paramount as it allows for verification of its existence (Bain, 2017), and can enable public access to the information. Mentioning the specific Act under which the decision was made demonstrates the researchers' ethical proficiency and helps editors, peer reviewers (and perhaps 'science sleuths') compare the stated procedures with legal requirements when in doubt.

Regarding informed consent, it is crucial to report the type of informed consent obtained, whether it was implicit, presumed ('opt-out') or in any other specific form. This information helps assess whether participants were adequately informed and gave consent in a manner that protected their rights and facilitated their understanding and voluntary participation. Waivers should be explicitly stated, as they are considered exceptional in biomedical research and require approval from an ethical review committee (which establishes a connection between the need for review and consent statements). If presumed consent was employed in the study (Singleton & Wadsworth, 2006), additional details about how information was provided and whether re-consent (Fons-Martínez & Diez-Domingo, 2021) was sought later should be provided. It is also important to specify from whom consent was sought, particularly in cases such as palliative care research, where both patients and their families may be involved. Family members in such studies may be the subjects of investigations or interventions, or they may be asked to contribute information or record symptoms. As noted by Casarett and Karlawish, such research covers 'a wide variety of issues, including family functioning, family perceptions, and the effect of the patient's illness on family members' health and wellbeing. Not only are family members the focus of studies and interventions, but they may also be asked to participate by providing information or recording symptoms' (Casarett & Karlawish, 2000, p. 133). Again, stating the Act under which the process fell is both indicative of researchers' level of understanding of the applicable rules and makes critical review possible. Requirements that a proper statement should include a fuller description of the informed consent process rest on the fact that the information required is comprehensive with the duty falling upon researchers (CIOMS, 2016, Guidelines 9, 10, 15, and 16). Failing to provide a thorough description of the informed consent process makes it impossible to assess the adequacy of the consent obtained (Xu et al., 2020).

Strengths and limitations of this study

The congruence of the present results with previous studies gives credibility to the conclusion that measures should be introduced to increase compliance with reporting standards especially when research concerns vulnerable persons in palliative care or at the end of life. We have suggested how journals could advocate for stricter standards. However, we should note that this study also has certain limitations. We cannot exclude the possibility that our results might have been different if we had included research articles from a more extended period, or from a broader range of research communities. Thus, it is unclear to what extent the results we have presented here represent the entire range of journals publishing research on palliative care and end-of-life care.

CONCLUSIONS

This study adds further evidence that ethical statements and informed consent processes are under-reported in published articles, apparently in many different fields of study. This is problematic as it creates uncertainty about the ethical rigour of studies, not least in terms of whether vulnerable participants receive special considerations because of their vulnerability. While research ethics training to make researchers aware of their obligations is important, having scientific journals requiring strict reporting standards is a faster way to change the present and problematic state of affairs.

AUTHOR CONTRIBUTIONS

Tove Godskesen and Stefan Eriksson designed the review protocol. Tove Godskesen and the medical librarians developed the search strategy and conducted the literature search. All authors screened and scored the papers. Tove Godskesen, Stefan Eriksson, and Knut Jørgen Vie drafted the manuscript. All authors were involved in data interpretation and critical revision of the manuscript for important intellectual content, and all have approved the final version. This means that all authors have (i) made a substantial contribution to the design of the work, or acquisition, analysis, or interpretation of data; (ii) drafted the article or revised it critically for important intellectual content; (iii) approved the version to be published; (iv) have participated sufficiently in work to take public responsibility for appropriate portions of the content.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The datasets used and analysed during the current study available from the corresponding author on reasonable request.

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APPENDIX

Cinahl, 2022-03-30			
Search no.	**Search terms**	**Results**	**Comments**
#1	Hospice Care OR Hospice Patients OR Hospice and Palliative Nursing OR Hospices OR Palliative Care OR Palliative Medicine [MeSH]	50,642	
#2	hospice* OR hospis OR palliative OR palliativ* OR palliasjon* [ti/ab]	48,473	
#3	#1 OR #2	66,055	
#4	sverige* OR svensk* OR swed* OR norge* OR norsk* OR noreg* OR norway* OR norwegian* [all fields]	61,065	
#5	#3 AND #4 NOT (Systematic Review[Publication Type]) *Filter: Publication date: 2019→*	146	
ProQuest Social science premium collection, 2022-03-30			
Search no.	**Search terms**	**Results**	**Comments**
#1	Hospice Care OR Palliative care [MAINSUBJECT.EXACT]	16,437	
#2	hospice* OR hospis OR palliative OR palliativ* OR palliasjon*	18,499	
#3	#1 OR #2	24,001	
#4	sverige* OR svensk* OR swed* OR norge* OR norsk* OR noreg* OR norway* OR norwegian* [all fields]	468,042	
#5	#3 AND #4 *Filter: Publication date: 2019→*	186	
PsycInfo, 2022-03-30			
Search no.	**Search terms**	**Results**	**Comments**
#1	Hospice OR Palliative Care [DE]	16,814	
#2	hospice* OR hospis OR palliative OR palliativ* OR palliasjon*	15,491	
#3	#1 OR #2	20,096	
#4	sverige* OR svensk* OR swed* OR norge* OR norsk* OR noreg* OR norway* OR norwegian*	109,365	
#5	#3 AND #4 *Filter: Publication date: 2019→*	119	
PubMed, 2022-03-30			
Search no.	**Search terms**	**Results**	**Comments**
#1	Hospice Care OR Hospice and Palliative Care Nursing OR Hospices OR Palliative Care OR Palliative Medicine [MeSH]	69,892	
#2	hospice* OR hospis OR palliative OR palliativ* OR palliasjon*[ti/ab]	82,531	
#3	#1 OR #2	108,565	
#4	sverige* OR svensk* OR swed* OR norge* OR norsk* OR noreg* OR norway* OR norwegian* [all fields]	655,008	
#5	#3 AND #4 NOT (Systematic Review[Publication Type]) *Publication date: 2019→*	573	
Web of science Core Collection, 2022-03-30			
Search no.	**Search terms**	**Results**	**Comments**
#1	hospice* OR hospis OR palliative OR palliativ* OR palliasjon* [ti/ab]	73,333	
#2	sverige* OR svensk* OR swed* OR norge* OR norsk* OR noreg* OR norway* OR norwegian* [all fields]	1,715,437	
#3	#1 AND #2 *Publication date: 2019→*	515	