How to Reveal Disguised Paternalism – Version 2.0

Niels Lynøe (niels.lynoe@ki.se)
Karolinska Institute

Ingemar Engström
Örebro University

Niklas Juth
Karolinska Institute

Research Article

Keywords: physician assisted suicide, disguised paternalism, hard and soft paternalism, value impregnated factual claims

Posted Date: August 4th, 2021

DOI: https://doi.org/10.21203/rs.3.rs-742099/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License

Version of Record: A version of this preprint was published at BMC Medical Ethics on December 1st, 2021. See the published version at https://doi.org/10.1186/s12910-021-00739-8.
Abstract

**Objectives:** To further develop an index for detecting disguised paternalism, which might influence physicians’ evaluations of whether or not a patient is decision competent at the end of life. Disguised paternalism can be actualized when physicians transform hard paternalism into soft paternalism by denying the patient’s decision-making competence.

**Methods:** A previously presented index was further developed to make it possible to distinguish between high and low degrees of disguised paternalism using the average index of the whole sample. We recalculated the results from a 2007 study to compare to a 2020 study. Both studies are about physicians’ attitudes towards, and arguments for or against, physician assisted suicide (PAS).

**Results:** The 2020 study showed that geriatricians, palliativists and middle aged physicians (46-60 years) had indices indicating disguised paternalism, in contrast with the results from the 2007 study, which showed that all specialties (apart from GPs, surgeons and older physicians) had indices indicating high degrees of disguised paternalism.

**Conclusions:** The proposed index for identifying disguised paternalism reflects the attitude of a group attitudes towards physician assisted suicide. The indices make it possible to compare the various medical specialties and age groups from the 2007 study with the 2020 study. Because disguised paternalism might have clinical consequences for the rights of competent patients to participate in decision-making, it is important to reveal disguised hard paternalism, which could masquerade as soft paternalism and thereby manifest in practice.

Introduction

Medical paternalism is an attitude that physicians may have towards patients, though this attitude is currently considered problematic. The patient-physician relationship is supposed to be based on patient-centered care with respect for the patients’ rights to participate in decision-making, which, in turn, is based on the principle of autonomy (1). In principle, patient autonomy means that there is no reason for a physician to make decisions about what is in a competent patient’s best interest. If they make decisions on behalf of a competent patient anyway, that is called **hard paternalism.** It can happen that a patient is considered to be not competent and a physician makes surrogate decisions in the best interest of such a patient; this is called **soft paternalism.** Even though there are differences among countries and cultures, a general tendency is that hard paternalism is considered outdated and inappropriate (2). The physician often still knows and understands more that the patient about medical matters, but this does not imply that he or she always knows what is in the patient’s best interest. The patient might have preferences and values that differ from those of the physician. For example, if a patient prefers a shorter life time with higher quality of life to a longer life with lower quality of life, there might be a genuine value-conflict with the physician, who could prefer to have it the other way around. In the end, however, after an adequate
amount of information has been acquired in order to prevent misunderstandings, a physician is supposed to respect a competent patient's values and preferences (3).

If a physician finds that a patient's preference is in conflict with that physician's basic values about what is harmful (e.g., it contradicts the physicians interpretation of the dictum "do no harm", also called the non-maleficence principle), then the physician might try to persuade the patient to change her or his mind about the things the physician thinks is harmful. In the attempt to persuade the patient, the physician might use different strategies, from soft nudges to hardcore paternalism where the physician makes surrogate decisions about what is for the patient's own good (4, 5).

Since physicians today are generally aware that hard paternalism implies disrespecting and wronging a competent patient, physicians' efforts to influence the decision making of patients is often unintentional. Instead, physicians may covertly express tacit values that unconsciously influence the provided information to the patient, or the evaluation of whether or not the patient is competent (4). A Swiss study about physicians' personal values indicated an increased risk among some physicians for arbitrariness when determining patients' decision-making capacities (6, 7). There are also indications that whether a palliative physician offers patients palliative sedation depends on that physician's own personal values (1, 4). Letting one's own values inadvertently influence evaluations of patients, especially in regards to the decision-making competency, can result in classifying a patient as incompetent. We refer to this process as disguised paternalism.

This kind of disguised paternalism was examined in a study from 2007 about Swedish physicians' attitudes towards physician assisted suicide (PAS) in which the physicians were also asked prioritize among different arguments for or against PAS (8, 9). In the context of this study, it is possible to develop an index of disguised paternalism (8). In the present paper, we report the results of our 2020 repeat of the 2007 study and further develop and validate this index of disguised paternalism as well as analyze its consequences.

Methods

In the 2007 survey, participants were presented with 10 fixed response arguments that were either in favor of PAS or against PAS, and they were asked to prioritize the arguments according to their own professional opinion about which arguments were most persuasive to them. In the 2020 survey, the number of fixed response options were reduced to four arguments. Two of these arguments favored PAS (a. based on the autonomy principle by itself, or b. based on the thinking that the autonomy principle should overrule the non-maleficence principle) and two arguments were against PAS (a. the patients do not know their own best interest, and b. the thinking that the non-maleficence principle should overrule the autonomy principle). The arguments against PAS are the disguised paternalism arguments (8, 9). Although there were more arguments for physicians to prioritize in the 2007 study, we have re-calculated this prioritization so that those answers are comparable with the 2020 study. In the 2007 study, 339 (out of 614) physicians had prioritized one of the same four arguments (8) that also were part of the 2020
The disguised paternalism index was calculated by taking the difference between how many respondents prioritized the two autonomy based arguments ($A$) and how many prioritized the non-maleficence-principle arguments ($NM$); the difference was then divided by the number of those who prioritized the $NM$ arguments:

$$\frac{(A - NM)}{NM}$$

The size of the difference determines the size of the index. The smaller the index, the higher degree of disguised paternalism and vice versa. If $NM$ is larger than $A$, the difference will become negative, which would be a very small index and accordingly a very high degree of disguised paternalism.

There are no certain boundaries for amounts of disguised paternalism. The idea is to compare the indices of the different specialties, different age groups, and whether the index changed from 2007 to 2020. In the present text, the dividing line between high and low amounts of disguised paternalism is based on the average index for that group – indices below the average index from the two study samples indicates a high degree of disguised paternalism (see Table 1).

Research ethical approval: The study was approved by the Swedish Ethical Review Authority, Dnr: 2020-01842.

**Results**

A comparison of the 2007 results to the 2020 results in terms of calculated indices for each specialty (and a separate index for palliative care physicians) is presented in Table 1. For the 2007 study, the average index 0.38, meaning that < 0.38 represents a high degree of disguised paternalism whereas > 0.38 represents a low degree of disguised paternalism. The corresponding average index for 2020 was 0.21.

**Discussion**

In the results of the 2007 survey, GPs and surgeons, together with the middle aged (46-60 years) and the oldest physicians (>61 years), had low (or in the case of the oldest physicians, very low) degrees of
disguised paternalism (that is, their indices are well over the 0.38 average). Geriatricians, internists, psychiatrists and oncologists had high degrees of paternalism (as indicated by indices less than 0.38), while the youngest age group (<46 years) had very degrees of disguised paternalism (as indicated by the negative index value).

Analysis of the 2020 survey results revealed a somewhat different pattern of disguised paternalism among the specialties. GPs, surgeons, and psychiatrists had low degrees of disguised paternalism, as did the youngest group of physicians and the oldest group of physicians (all above the 0.21 average). Internists, oncologists, and the middle-aged group were slightly below the average, indicating a high level of disguised paternalism, while geriatricians, palliative physicians had negative indexes, indicating that the physicians in these two specialties had quite high degrees of disguised paternalism.

Comparing the 2007 indices to the 2020 indices, we can see that the groups that changed the most in terms of relative amounts of disguised paternalism are geriatricians, psychiatrists, and the youngest physicians. Geriatricians were less paternalistic in the 2007 study than the 2020 study; in contrast, psychiatrists and the group of youngest physicians were more paternalistic in 2007 than 2020. The main results of the 2020 study showed that most specialties, with the exception of geriatricians, were more pro-PAS in 2020 than they were in 2007 (9). (In the 2020 study, a majority of palliative physicians were against PAS, but no comparison to 2007 is possible.)

Comparing the age groups, we see that in 2007, the youngest group of physicians had a high level of disguised paternalism, while the middle-aged and oldest group did not. In 2020, the middle-aged group had a high level of disguised paternalism, while the oldest and youngest did not. Of course, many individual physicians who were in the youngest group in 2007 have aged into the middle-aged group in 2020. If this trend continues, we might expect that a survey performed in 2033 would reveal that middle-aged physicians (i.e., today’s young physicians) would have a lower degree of disguised paternalism than today’s middle-aged physicians.

Geriatricians and palliative physicians

The most relevant result for discussing PAS and other end-of-life issues is the high level of disguised paternalism among geriatricians and palliative care physicians. In 2007, this specialty had a high level of disguised paternalism, but in 2020, the index became negative, indicating an even higher degree of disguised paternalism. This trend in this specialty might reflect a reaction to the ongoing covid-19 pandemic, where many elderly and frail patients, sometimes also cognitively impaired, died under conditions that, under normal circumstances, would have meant they would have been offered to palliative care (10) – even the dysphemism “euthanasia” was used in the Swedish debate when discussing elderly patients with covid-19 (11). The majority of these patients would not have been referred to emergency hospitals under normal conditions, but during the pandemic, patients suffering from covid-19 pneumonia was considered to be a type of assisted dying (11). The use of terms like ‘palliative care’ and ‘euthanasia’ might have influenced geriatricians and their attitudes towards the PAS issue, and stressed the importance the non-maleficence principle. Some of the geriatric patients may have been physically
frail with several comorbidities, but still mentally competent, and we do not know what they would have preferred. Some of these patients might also have a dementia diagnosis, and it is possible that geriatricians were trying to protect these non-competent patients. When patients are not competent and the physician makes decisions on their behalf, this is referred to as soft paternalism. Disguised paternalism is not about soft paternalism, but rather about hard paternalism, and disguised paternalism is actualized when, for instance, a geriatrician transforms hard paternalism to soft paternalism by considering a competent patient as non-competent as a way to justify their decisions.

The other specialty with very high disguised paternalism index was palliativists. Palliative care physicians take care of many suffering patients at the end of life, and seems reasonable to ask whether this disguised paternalism influences decisions made by these physicians. There are indications that palliativists’ personal values influence whether or not they apply palliative sedation (1, 4, 12), which is particularly relevant because “good palliative care” together with palliative sedation is often claimed to be an adequate or even better alternative to PAS (10). An international trend is that palliativists are currently more inclined to provide continuous deep sedation on a patient’s request (13, 14). But this trend is not yet observable in Sweden, which is problematic because continuous deep sedation on request could in many (though not all) cases replace PAS (15). Some palliativists seem to have not only disguised paternalism, but also the form of paternalism in which they claim that they are protecting a patient’s autonomy rather than respecting it. Since such palliativists are referring to autonomy, their attitude becomes paternalism in the name of autonomy, which is a sophisticated form of disguised paternalism (16). In practice, a patient might request continuous deep sedation, but in order to protect the patient’s autonomy, superficial and intermittent palliative sedation is provided instead, even against the patient’s preferences (5). Such a patient might be brought to consciousness up to four times per day in order to be asked whether or not they would like to continue being sedated (1, 4). Representatives from the general public have described such procedure as macabre or cruel and non-humane (17).

As can be seen from (especially) palliativists, disguised paternalism might have serious consequences for patients within palliative care. If such patients are truly competent, their wishes and preferences at the end of life should be respected. The 2020 study indicated that one in four palliativists supported PAS, which still leaves a clear majority against PAS, and it has been shown that palliativists’ personal values influence their practice and their regard for patients’ wishes (1, 4). Disguised paternalism is not solely an academic issue – it has consequences when equal cases are not treated equally – and, accordingly, disguised paternalism should be revealed when possible and counteracted.

**Strengths And Limitation**

Several more fixed options for and against PAS were presented in the 2007 survey than the 2020 survey, which meant that we had to eliminate 275 respondents when recalculating the 2007 results to compare with the 2020 results. The 2007 study used two combined arguments, “non-maleficence should overrule the autonomy principle argument” and “the patient does not know her/his own best”, and we subtracted these collapsed numbers from all other arguments and accordingly the difference became somewhat
higher (compared to the 2020 study) and accordingly also the average index. Using the average index as the boundary for each separate study makes it somewhat easier to compare the two studies.

It should be stressed that the indices are associated with the PAS issue, and therefore the results should not be generalized to other areas and issues. The average index would fluctuate based on the participants and circumstances, but would probably systematically change depending on when the survey is done and how controversial the main issue is. Previously conducted studies indicated that the influence of physicians’ own values and preferences are more expressed on issues that are more controversial, and PAS is a controversial issue, at least in the Swedish medical context (18).

Conclusions

The study suggests that the proposed index be used as an indicator of disguised paternalism regarding competent patients and that disguised paternalism might be present when reasoning about a controversial issue such as physician assisted suicide. What the index tells us is that disguised paternalism is quite common among certain age groups of physicians as well as certain specialties. Overall, there was less disguised paternalism in the 2020 study than the 2007 survey. Palliativists, who are the physicians actually treating suffering patients at the end of life, showed the highest degree of disguised paternalism, which could have implications for when and if continuous deep palliative sedation is offered.

Declarations

Funding

There was no specific funding for this study.

Competing interests

None of the authors had any conflict of interests to declare.

Availability of data and material

Data might be made available by contacting the corresponding author.

Code availability

The WHO based software program Epi-Info was applied when performing the registration and analysis of data. The data from this study is available by contacting the corresponding author.

Authors’ contributions

NL conducted the analyses and wrote the first draft, after that NJ and IE critically improved the manuscript. All authors contributed substantial and intellectual equally; all authors also approved final
version.

**Ethics and consent to participate approval**

The study was approved by the Swedish Ethical Review Authority, Dnr: 2020-01842. The methods were carried out in accordance with the Declaration of Helsinki.

Since it was a questionnaire based survey we did not obtain a specific consent for participating or publication and there were no risks that any specific participant could be identified. This procedure was also approved by the Swedish Ethical Review Authority (Dnr: 2020-01842). The participants were informed about the purpose of the study in the introduction letter.

**Acknowledgement**: Not Applicable.

**References**

1. Lynøe N, Helgesson G, Juth N. Value-impregnated factual claims may undermine medical decision-making. *Clin Ethics* 2018; 13(3): 151–8.

2. Gillon R. Ethics needs principles—four can encompass the rest—and respect for autonomy should be "first among equals". *J Med Ethics* 2003; 29(5): 307–12.

3. Mulley AB, Trimble C, Elwyn G. Stop the silent misdiagnosis: Patients’ preferences matter. *BMJ* 2012; 345: e6572. doi: 10.1136/bmj.e6572.

4. Lynøe N. Physicians’ practices when frustrating patients’ needs: A comparative study of restrictiveness in offering abortion and sedation therapy. *J Med Ethics* 2014; 40(5): 306-9.

5. Bailo L, Vergani L, Pravettoni G. Patient Preferences as Guidance for Information Framing in a Medical Shared Decision-Making Approach: The Bridge Between Nudging and Patient Preferences. *Patient Prefer Adherence* 2019; 13: 2225-31.

6. Hermann H, Trachsel M, Biller-Andorno N. Physicians’ personal values in determining medical decision-making capacity: A survey study. *J Med Ethics* 2015; 41(9): 739-44.

7. Hermann H, Feuz M, Trachsel M, Biller-Andorno N. Decision-making capacity: from testing to evaluation. *Med Health Care Philos* 2020; 23(2): 253-9.

8. Lynøe N, Juth N, Helgesson G. How to reveal disguised paternalism. *Med Health Care Philos* 2010; 13(1): 59-65.

9. Lynøe N, Engström I, indblad A, Sandlund M, Juth N. Trends in Swedish physicians’ attitudes towards physician-assisted suicide: A cross-sectional study. *BMC Med Ethics* 2021 Jul 2; 22(1): 86. doi: 10.1186/s12910-021-00652-0.

10. Bielza R, Sanz J, Zambrana F, et al. Clinical Characteristics, Frailty, and Mortality of Residents With COVID-19 in Nursing Homes of a Region of Madrid. *J Am Med Dir Assoc*. 2021; 22(2): 245–252.e2. Published online 2020 Dec 11. doi: 10.1016/j.jamda.2020.12.003
11. Swedish geriatric professor: “Treating elderly covid-19 patients with morphine is euthanasia.” In *Dagens Nyheter* (Daily News) downloaded 25 May 2021. https://www.dn.se/nyheter/sverige/geriatrikprofessor-det-har-ar-aktiv-dodshjalp/

12. Hermann H, Trachsel M, Elger BS, Biller-Andorno N. Emotion and Value in the Evaluation of Medical Decision-Making Capacity: A Narrative Review of Arguments. *Front Psychol* 2016; 26:7:765

13. Robijn L, Cohen J, Rietjens J, Deliens L, Chambaere K. Trends in Continuous Deep Sedation until Death between 2007 and 2013: A Repeated Nationwide Survey. *PLoS One.* 2016; 11(6): e0158188. doi: 10.1371/journal.pone.0158188. eCollection 2016.

14. Madelon T Heijltjes MT, van Thiel, GJMW, Rietjens JAC, van der Heide A, de Graeff, M van Delden JJM. Changing Practices in the Use of Continuous Sedation at the End of Life: A Systematic Review of the Literature. *J Pain Symptom Manage* 2020; 60(4): 828-46.e3. doi: 10.1016/j.jpainsymman.2020.06.019.

15. Bhaskar A. The inescapable truth: palliative care is not enough – we can and should legislate for assisted dying. *BMJ* Opinion. 25 sep 2019.

16. Sjöstrand M, Eriksson S, Juth N, Helgesson G. Paternalism in the name of autonomy. *J Med Philos* 2013; 38(6): 710-24.

17. Lindblad A, Juth N, Fürst CJ, Lynöe N. Continuous deep sedation, physician-assisted suicide, and euthanasia in Huntington’s disorder. *International Journal of Palliative Nursing* 2013; 16 (11): Published Online:28 Sep 2013https://doi-org.proxy.kib.ki.se/10.12968/ijpn.2010.16.11.80019

18. Lynöe N, Björk J, Juth N. Is healthcare providers’ value-neutrality depending on how controversial a medical intervention is? Analysis of 10 more or less controversial interventions. *Clin Ethics* 2017; 12(3):117-23.

**Tables**

**Table 1.** The disguised paternalism indices among the different specialties and age groups for 2007 and 2020. The average indices are used to divide between a high degree of disguised paternalism (<0.38 and <0.21) and a low degree of disguised paternalism (>0.38 and >0.21). GPs=General practitioners. Palliative medicine was established as a specialty in 2015 and therefore not included in the 2007 study.
| Specialties   | Disguised paternalism indexes for specialties and age groups 2007 | Disguised paternalism indexes for specialties and age groups 2020 |
|--------------|-----------------------------------------------------------------|----------------------------------------------------------------|
| GPs          | $(40 - 17)/17 = 1.35$                                           | $(54 - 41)/41 = 0.32$                                           |
| Surgeons     | $(39 - 19)/19 = 1.05$                                           | $(59 - 36)/36 = 0.64$                                           |
| Geriatricians| $(30 – 25)/25 = 0.2$                                            | $(44 - 45)/45 = -0.02$                                          |
| Internists   | $(31 - 28)/28 = 0.11$                                           | $(63 - 53)/53 = 0.19$                                           |
| Psychiatrist | $(27 - 27)/27 = 0.00$                                           | $(54 - 35)/35 = 0.54$                                           |
| Oncologists  | $(27 - 26)/26 = 0.04$                                           | $(47 - 41)/41 = 0.15$                                           |
| Palliativists| -                                                               | $(15 - 30)/30 = -0.5$                                           |

**Age groups:**

| Age groups   | Disguised paternalism indexes for age groups 2007 | Disguised paternalism indexes for age groups 2020 |
|--------------|---------------------------------------------------|--------------------------------------------------|
| <46 years    | $(59 – 67)/67 = -0.12                             | $(144 – 99)/99 = 0.45                            |
| 46-60 years  | $(96 – 67)/67 = 0.55                              | $(102 – 111)/111 = 0.08                          |
| >61 years    | $(41-13/13= 2.2                                   | $(94-70)/70 = 0.34                               |
| Average      | $(196 – 142)/142 = 0.38                           | $(340 – 280)/280 = 0.21                          |