

Roskilde **University**

Inequity in palliative care

class and active ageing when dying Aamann, Iben Charlotte; Dybbroe, Betina

Published in: Social Theory and Health

10.1057/s41285-023-00196-w

Publication date: 2023

Document Version Publisher's PDF, also known as Version of record

Citation for published version (APA):
Aamann, I. C., & Dybbroe, B. (2023). Inequity in palliative care: class and active ageing when dying. Social Theory and Health, Online First. Advance online publication. https://doi.org/10.1057/s41285-023-00196-w

General rightsCopyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
 You may not further distribute the material or use it for any profit-making activity or commercial gain.
 You may freely distribute the URL identifying the publication in the public portal.

Take down policy

If you believe that this document breaches copyright please contact rucforsk@kb.dk providing details, and we will remove access to the work immediately and investigate your claim.

Download date: 19. Jan. 2024

ORIGINAL ARTICLE



Inequity in palliative care: class and active ageing when dying

Iben Charlotte Aamann^{1,2} · Betina Dybbroe¹

Accepted: 3 September 2023 © The Author(s) 2023

Abstract

The purpose of this article is to explore social inequity in palliative care in Denmark, a country that is seen as a stronghold of universal health care. Using data stemming from 2 years of research, we have selected two cases for analysis. They consist of palliative conversations with two quite different patients. Drawing on sociocultural class theory, we find that the conversations involve social exclusion processes due to discourses of active ageing. We find that one privileged patient performs in line with an entrepreneurial self and is supported by the nurse. The other, disadvantaged patient performs in a passive way, and the conversation mainly alleviates the disrespect he has experienced in healthcare encounters. We conclude that palliative care reinforces classifying practices and distinctions between "good" and "bad" patients, when active ageing becomes a dominant factor. We suggest improving the quality and sensitivity of medical training and call for increased reflexivity among professionals on the unequal situation of patients in order to reduce inequity in access to health care when close to death.

Keywords Social class · Palliation · Active ageing · Inequity in health care

Introduction: social inequality in health despite universal healthcare

In this article we investigate how palliative care is affected by discourses of active ageing. We analyse palliative care conversations and our specific interest lies in how social differentiation is embedded in discourses of active ageing which imply a middle-class ideal of a self-entrepreneurial subject.

All citizens in Denmark are entitled to free public healthcare. Elderly and palliative care is also a public responsibility, although private services co-exist. Although

Published online: 28 September 2023



[☐] Iben Charlotte Aamann ica@ruc.dk

Health Promotion Research Centre, Roskilde University, Universitetsvej 1, 4000 Roskilde, Denmark

Section of General Practice, Copenhagen University, Copenhagen, Denmark

universal healthcare is fundamental to the Nordic welfare model, social inequity in health is highly prevalent (Diderichsen et al. 2011). Recent years have seen increasing research interest in unequal access to healthcare in Denmark (Behandlingsrådet 2023; Rigsrevisionen 2019; Pedersen et al. 2021). It has, therefore, been well described in quantitative studies how Danish healthcare is unequally distributed along lines of socio-economic variables.

However, very few studies illuminate how specific care practices at the microlevel are influenced by social differentiation. Further, not many studies explore how discourses of active ageing actually operate as norms of segregation through professional practice embedded in the institutions of the Danish welfare state. With this article, we aim to contribute to existing quantitative research by examining qualitatively how social inequality is reproduced in palliative care practices.

Palliative care is considered important for society in order to cut the increased costs of life-prolonging treatment (May and Cassel 2018), and important for patients if side effects of futile treatment make prolonging life a burden for patients and families (Davis 2015; Wiersma et al. 2019). Greater longevity with life-threatening diseases has also increased the focus on palliative care. This ideally involves a focus on alleviating "total pain" (Clark 1999), i.e. an awareness of social and financial problems, physical challenges, and existential and mental problems in facing death (see e.g. Sundhedsstyrelsen 2017), and the notion that the needs of patients with life-threatening illness must be identified early, based on the assumption that this will provide greater clarification as death approaches.

Healthy citizenship and inequity when ageing and dying

It is well argued that Western health policies rest on "a paradigm of neo-liberal governmentality through inculcating responsibility in individuals who are compelled to take up the role of health entrepreneurs, acting upon their bodies and selves to achieve an idealised form of healthy citizenship" (Crawshaw 2012, p. 201). A key feature of this is the emergence of a particular focus on "the self". This "psychologisation" or "governmentalisation" of human existence (Rose 1990; Walkerdine 2003), establishes a political logic dominated by a form of "human" profitability (Skeggs 2014). People should, thus, be "subjects of value" (Türken et al. 2015, p. 34), constantly preoccupied with a "healthy lifestyle" and "self-realisation" to enhance their symbolic value all the way to death.

The idealised self-optimising subject is permeating society, culture and the way healthcare institutions organise their handling of ageing and death. As a consequence, successful ageing discourses have gained ground (Katz 2000). Harris et al. point out how these discourses often portray successful ageing in a way that "emphasized older adults' ability to choose the way they age, through making the right decisions about their lifestyles, diets, and attitudes" (Harris et al. 2016, p. 378). They also argue that this generates an "ideal of old age or 'senior' citizenship" (ibid.). Carter examines discourses about successful and frail seniors and considers it likely that: "...social structures such as racism, sexism, and neoliberalism may



impact the way patients are placed into the social categories of successful agers or frail agers" (Carter et al. 2020, p. 6).

Our analysis explores how these overall macro tendencies establish themselves at the micro level. The question we examine is how these new distinctions between the successful ageing of subjects who take on "responsibility" for their health and the "resigned", "irresponsible", physically deteriorating agers are informed by social class.

Richards notes that there has been an "equity turn" in palliative care research (2022) and advocates for researchers to take into account "the wider political, institutional, and economic conditions" (p. 10) in which poverty comes to exist and healthcare is delivered. Further, she calls for a shift in attention from measurement to a deeper awareness of explanatory factors (p. 1).

This article contributes to this turn by exploring qualitatively how social class is reflected in palliative communication in ways which create unacknowledged and unarticulated practices of distinction which might lead to differential treatment. This is important because of the risk of reproducing inequity.

Social class and classifying practices

The understanding of class in this article draws on Bourdieu, since he mainly focused on the reproduction of middle-class privileges at the expense of the lower classes (Bourdieu et al. 1999). This enables us to understand how class is reproduced in the universal welfare context of the Danish healthcare system and to explore class-based implications of different patients receiving palliative care in healthcare facilities that are embedded in middle-class norms and cultures (Aamann and Erlik 2023; Aamann 2020).

Bourdieu insisted that cultural practices should be treated as co-constitutive of how class relations are configured (2010). He also focused on the persistence of structures, by developing the concept of habitus to comprehend how class structures are inscribed in people's bodies and minds (Bourdieu 1990). Importantly, he reasoned that forms of capital other than economic, such as cultural and symbolic, must be included in explorations of social inequality (Bourdieu and Passeron 2006).

The concept of class has traditionally been one of the major sociological concepts, but in the last 20–30 years, it has lost some of its strong position. Part of the explanation lies in the fact that industrial society with its clear stratification has been dismantled. However, the shift from industrial to financial capitalism, also known as neoliberalism (Tyler 2015), has not removed social inequality but rather increased it. In this context, it appears that class is still highly active but in more diffuse ways. Skeggs insists: "... class is so insinuated in the intimate making of self and culture that it is even more ubiquitous than previously articulated, if more difficult to pin down, leaking beyond the traditional measures of classification" (Skeggs 2005, p. 968).

Neoliberalist discourses have, thus, been said to marginalise class as an explanatory factor for inequality (McLaren 2005), neglecting the structural circumstances that determine individual choices. However, Lamont (2012) states that neoliberalism



reinforces class differences in terms of assessing people's moral value. Class can, thus, be understood not only as socio-economic position or as forms and amounts of capital, but also as "circulating through symbolic and cultural forms, i.e. the means by which people become judged as morally worthwhile, or as having the right kind of knowledge or 'taste'" (Lawler 2005, p. 797). Seen from this perspective, class works through relational processes that comprise "both a social filter and a key mechanism individuals utilise in placing themselves and others" (Reay 1997, p. 226).

Sointu (2017) explores the reproduction of inequality in medicine; she finds that ideas of "good" and "bad" patients are at play in medical education and that these ideas are embedded in class differences. In this article, we explore how these "classifying practices" of value assignment shape palliative communicative encounters between professionals and end-of-life patients. Howarth (2007) and Conway (2013) criticise the sociology of death for not including class, which could reveal how people of different socio-economic status relate differently to death. Despite increased interest in inequity in palliative care research, there are still remarkably few studies with this qualitative, sociocultural class perspective.

Especially in the Nordic universalist welfare states with their redistributive aims, there has been little research into the influence of social class in healthcare and even less in relation to palliation and death. Although social differences are discreetly admitted, Denmark is rarely considered as having a marked class system, but is rather seen as one of the strongholds of the welfare state (Faber et al. 2012). However, despite comprehensive economic redistribution and universal welfare coverage, Denmark does have a range of the traditional class inequalities well known in the UK and the US (Caspersen 2021; Udesen et al. 2020). This makes Denmark a particularly strong case for an exploration of how classifying practices, through attribution of value, impact palliative encounters.

Palliation via communication

Healthcare increasingly involves communication (Pors 2014), with patient involvement as a key concept (Phillips and Scheffmann-Petersen 2020). Firstly, enhancing patients' ability to communicate is expected to increase equality (Aamann and Olesen 2020). Secondly, it is assumed that palliative care is improved through reflexive dialogue in which a "clear and open communication about death is encouraged" (Olson et al. 2020, n.p.), partly to facilitate collaborative planning aimed at achieving a "good death". McCreaddie states that end-of-life communication is considered entirely positive, a "moral imperative" (2011, p. 46).

However, the requirement for patient-centred care may clash with the ideal of a clear, open and euphemism-free dialogue, because it implies respect for the preferences of patient and family: patients might wish to avoid open communication, prefer euphemisms, and understand a "good death" differently from professionals and perhaps even their relatives. These arguments, thus, indicate a problem of assuming that dying people want to articulate their suffering and to participate actively in planning their final days.



Materials and methods

In 2018, the public authorities in one of the five regions of Denmark expressed a desire to enhance palliative care. The aim of our research was to follow the spread and effects of a conversation tool.

The tool was developed by the local health authorities in collaboration with professionals and patients with the purpose of facilitating palliative dialogues across hospitals and communities. The concept of "total pain" guided the tool, which focused on psychosocial challenges by asking patients questions like "How are you doing?", "Is there anything about the disease you would like to know?" "What gives you quality of life?" "What troubles you?" and "What do you hope the healthcare system and healthcare professionals can do for you?". The tool was formed as a small booklet with one question on each page and space to write notes below each question.

Aamann and Dybbroe were hired to do an evaluative research project. This included two work packages: one focused on patients and their perspectives (2018–2019) and the other on organisational frameworks and interprofessional cooperation (2019–2020). The research was designed as a multisited ethnographic investigation (Marcus 1995) and the palliative conversation tool was followed at different sites. Following the understandings of reflexive ethnography (Davies 1999) and critical ethnography (Madison 2004), we were aware of observed practices as performance of cultures.

Twelve patients were chosen by the professionals and followed by the researchers. The patients had various life-threatening diseases and were at different stages and ages. Fourteen palliative care clinicians and three GPs also participated. The majority of the palliative care clinicians had a bachelor's degree in nursing, were very experienced in the field and had had specialised training in palliation.

As white, female, middle-class researchers it was easy to blend in to the field. We observed palliative conversations, and invited patients and professionals to share their stories, experiences and perspectives on these conversations. We, therefore, organised two focus groups with professionals, and a workshop with 16 professionals from different parts of the region. We also had discussions with the early palliative care board, representing patients, researchers and professionals. Finally, we regularly discussed our observations with patients, professionals and relatives. The actors involved were, thus, never objects of scrutiny, but active participants (Fetterman 2018).

All participants gave their informed consent, both orally and through their active participation (see Thagaard (1998) and Tjørnhøj-Thomsen and Hansen (2009) for the question of informed consent and ethical reflexivity). Participation was completely voluntary for both patients and professionals, and they were informed that they could withdraw from the project at any time. Field notes were written without personally identifiable information and with pseudonyms for names of places and people, as well as changes of gender, diagnosis, etc., where this was considered irrelevant to the study.



The data consisted of over 317 pages of transcribed interviews, informal every-day conversations and field notes. After the fieldwork had ended, the data were analysed using a dialogical communicative approach (Olesen et al. 2018). We noted differences and their relation to sites and contexts, which produced the research theme of "inequity in palliative care communication practices".

The cases

We have selected two patients at opposite ends of the Danish class society, in terms of their different forms and amounts of capitals. This is interesting because the palliative care provided was identical and the same nurse initiated the palliative conversations.

The two cases are chosen because they illuminate patterns identified in the whole data set. As noted by Flyvbjerg:

Atypical or extreme cases often reveal more information because they activate more actors and more basic mechanisms in the situation studied. In addition ... it is often more important to clarify the deeper causes behind a given problem and its consequences than to describe the symptoms of the problem and how frequently they occur. Random samples emphasizing representativeness will seldom be able to produce this kind of insight; it is more appropriate to select some few cases chosen for their validity. (Flyvbjerg 2006, p. 229)

The cases work like a magnifying glass for differentiation practices occurring more widely across the data. Both patients are male; they have different, fatal lung diseases. Patient 1, the privileged patient, is approximately 80 years old. He has not yet been declared terminal when Aamann meets him. The disadvantaged patient, Patient 2, is about 70 years old. He has recently been declared terminal. This life expectancy is representative of social inequality in health in Denmark. Life expectancy for men with little education is seven years shorter than for well-educated men (Udesen et al. 2020). The men live under the same local authority. Patient 1 lives in a busy town, while Patient 2 lives in a small village at some distance from main roads, which is a common difference between wealthy and poor Danes (Andersen et al. 2021). A few days before the conversation, the men received the small booklet. They were asked to prepare for the conversations by reflecting on the questions and noting down the main points.

Case 1: praising the successful and active agers

The palliative care nurse explained to Aamann, before the care visit: he is well-off. The nurse has helped Patient 1 decide whether to set up a fund, as there are no inheritors. The amount is around 55 million Danish kroner.

¹ By comparison, an economist earns an average of DKK 21.6 million during his/her entire working life (https://nyheder.tv2.dk/business/2010-11-22-saa-meget-tjener-du-paa-et-helt-liv), last visited 2023.01.05.



Patient 1 lives in a new two-floor flat near the town's lively shopping and pedestrian street. There is a door phone and a wide, comfortable staircase, with a large roof terrace between the floors with lush lavender in flower pots and neatly arranged wicker garden furniture. Patient 1 and his younger friend greet us in the hall and show us into the first living room. We see two sofa sets and many oriental, antique figurines, vases and lamps, clearly expensive collectibles. At the other end of the room is a large, private roof terrace with panoramic views of the marina.

Patient 1 has not written anything in the booklet, he says casually, but they have talked about it, Patient 1 and his friend assure us. "That's quite OK", says the nurse reassuringly, even though patients are supposed to write their answers on the dotted lines under each question.

The conversation begins as the nurse asks: "How are you doing?" Patient 1 explains that his situation is stable; the disease has not changed recently. He can also see that "many of the people I went with [to fitness training], they HAVE gone". He mentions a 60-year-old who "has already gone". "But", says Patient 1, "they didn't do anything either. I have lots of things to keep me occupied: my cottage, my garage, etc".

The conversation turns to important everyday things and life quality. Patient 1: "Well, I reckon it's all about shopping a bit, talking to people and driving around a bit, you know". Patient 1's friend: "And when you go and do things in your garage". He has recently bought the garage and "does some business with cars". Nurse: "And it's good exercise for your lungs, getting out and about".

The nurse wonders whether Patient 1 ever has bad days. Yes, but then he just lies on the sofa. She nods approvingly. Patient 1 does not have breathing problems when sitting down and otherwise, he says, it is a bit like exercise: "You get short of breath, then you just have to stop and catch your breath and then you continue a bit later". The nurse praises him: "That's the right attitude!"

Now the nurse asks if there is anything about the disease Patient 1 would like to know. They talk about the future. Patient 1 is worried about the stairs and has been out looking at some accommodation for seniors: "Yes, of course I could buy a small flat, but that doesn't solve my problem of being with someone ...". The nurse says: "We'll find a solution" and explains about care assessors. She also writes down her phone number: "You are always welcome to call me".

Patient 1 suggests they stop talking, because the cleaning help is coming. The nurse asks if it is a private company, but they are from the council; he receives cleaning help one hour a week.

The next question is about hope. Patient 1 hopes that he will continue to be able to drive his car, so he can get around. "Does he worry about anything", the nurse asks. "Nah!" he replies: "Cause I'm not the type to complain about everything". The nurse asks: "How do you feel about our talk?" Patient 1 answers, reclining on the sofa: "Well, it was fine, I thought—to talk a bit about everything".

Patient 1's argument that other participants in the rehabilitation group have already died because they did not "do anything" forms part of the active ageing discourse: death can be postponed through activity. Patient 1's own level of activity, thus, seems to confirm his value: because he is enterprising, he succeeds in keeping



the disease at bay and appears as a "valuable" self who takes responsibility for his own health.

Interestingly, however, Patient 1's activities are not primarily physical exercise: he drives around, talks to people, visits his cottage and conducts some car business in his new garage. Yet the nurse believes it helps his lungs. By linking Patient 1's social activities to keeping his lung disease in check, the nurse helps Patient 1 to understand himself as someone who takes responsibility for his own health and who actively fights the progression of the disease.

Although Patient 1 has not prepared properly for the meeting by writing in the booklet and sometimes just "lies on the sofa", he is met with respect and recognition from the nurse. Patient 1 is, thus, continuously supported by the nurse's approving remarks. She also places him and herself in the same boat by establishing a "we" and by giving him her direct phone number.

The appreciative nature of the conversation seems to draw on precisely the discourses of active ageing. The conversation supports Patient 1 and for him, old age is apparently, as it is promoted, "the longest holiday of your life" (Gilleard and Higgs 2011, p. 137). This conversation is about (confirming and supporting) Patient 1's quality of life and it is, thus, an example of comforting and caring palliative communication.

Let us now turn to the second case:

Case 2: misrecognition of disadvantaged agers

Patient 2 is a retired manual worker; besides his lung disease, he also has a pace-maker. His wife works in a factory and is, therefore, often away from home. They live in a small village without shops. Many houses are dilapidated with scruffy facades. They live in one of the older houses, opposite an abandoned factory with broken windows and a collapsing roof. In their garden are numerous rubbish bags and empty cigarette packets. In the hall is a large cat box with gravel around it, and various items scattered about on a small chest with no drawers.

Aamann joined the nurse when she visited the family at their home in order to have a supportive talk with the wife of Patient 2. At the time of the palliative conversation with Patient 2, he is not at home, but has a two-week stay at the care facility where the nurse works. The nurse introduces Patient 2 on the way to his room by saying: "There are some problems with compliance". He continues to smoke and refuses to exercise: "He only talks about it but doesn't do anything about it". He has come to the facility to exercise, but he "doesn't want to get out of bed". But Patient 2 is also there to give his wife some respite, the nurse explains. "Recently there was a conflict, he couldn't move from his bed to the car, he thought he couldn't get into a wheelchair, but with a little pressure he managed it", the nurse explains.

We enter Patient 2's room. It exudes institution with worn furniture, a neutral poster on the wall, practical cold lighting from tubes in the ceiling. There is a loud TV and a small bedside table full of boxes of medicine, bottles of pills, juice, a radio, a thermos flask, coffee cup and sugar lumps. He is lying in bed smoking an e-cigarette.



Patient 2 says the booklet is on the table. The nurse searches there in piles of newspapers, while Patient 2 assures her that he and his wife "have done as they were told": last night they went through the booklet and his wife has written in it. "But maybe she took the booklet home with her", says the nurse, "let's use my booklet instead".

The nurse starts the conversation by asking Patient 2: "How are you doing"? Patient 2 does not seem happy with the place he is in. He says: "it is worst in the morning. They come with so many things and activities, it gets too much", and then he gets short of breath and panics. He also tells me: "One day I had stool and she wouldn't change my pad unless I could get up myself. And I couldn't. And then she left". When his wife came later, she got very angry: "She could see the mess in my bum", he says. The nurse rounds off the topic by saying: "That doesn't sound reasonable. You had a need, which was met by a demand that you couldn't fulfil".

The conversation turns to important everyday things and life quality. Patient 2 is happy that his wife gets a little respite. She has bad arthritis and is burdened by caring for her ill husband and by her physically exhausting work. The nurse explains about the difference between the diseases: "The lung disease is something you will die from, while the arthritis is very painful but not life-threatening". She continues: "You know it's a progressive disease where you get worse and worse? Have you thought about deactivating the pump function when it's really bad?" Patient 2 replies quickly and breathlessly: "No and I don't think we should talk about it either, because then I'll just lie here thinking about it! But... I've got some leaflets at home I could look at".

Now the nurse asks if there is anything else about the disease Patient 2 would like to know. He cannot remember. Nurse: "Is it perhaps difficult to describe it with words? Have you tried to write the thoughts down?" Patient 2 says his eyes are getting worse and that he cannot really read or write any more. Nurse: "Have you been to an optician like I have suggested earlier?" "No...", Patient 2 sighs heavily: "cause we cannot really afford new glasses and I can't apply for financial support, cause I don't know how to fill out the forms online". He has asked the staff at the care facility, but they are busy and the same goes for the cleaning help at home – they come for one hour every three weeks and they move on quickly. The nurse offers to help him to apply. He seems grateful.

"Do you worry about anything?" the nurse asks. "Yes, 'cause they don't come when I call them. They just say, 'Someone else is in a worse state than you'." When the nurse asks Patient 2 what he hopes for, he replies: "That the staff ask me how I am. And maybe chat a bit.

Patient 2 is clearly having difficulty in living up to the implicit norms of active ageing and exercising. He lies passively in bed watching television or listening to the radio while smoking. He also gets stressed when the nurses show up in the morning with a lot of activities. In relation to the focus on people's will and ability to "take on responsibility", Patient 2 does not perform legitimately. He is not a "successful ager" as he does not exercise or show any desire or ability to conform to "active ageing" or a "healthy lifestyle".



It is interesting that the nurse says to Aamann that Patient 2 does not "want" to get up and "only talks about it", suggesting laziness and lack of willpower and self-discipline, or even disobedience. By contrast, Patient 2 himself says he cannot get up.

The comment about the refusal to change Patient 2's pad is intended to show that the nurse acknowledges Patient 2's situation, but it is also a value judgement on his performance and his situation: it does not state that the demand was "unreasonable", merely that Patient 2 "was unable" to fulfil it, which, thus, makes him appear indirectly responsible.

Patient 2 clearly prefers to live his final days without considering how and when death might occur. He does not want to talk about it, although he mentions some leaflets, perhaps to appear obliging instead of rejecting the nurse's suggestion. This theme appears in the conversation at a time when the talk was supposed to be about important everyday things and life quality.

Although the palliative care here works as a form of "social palliation" for Patient 2, as he gets to complain about his problems and is partly supported by the nurse, it is nevertheless remarkable that the main "relief" for Patient 2 is to talk about the disrespectful way he is treated by healthcare workers.

Results: different lives and different palliative encounters

The professionals' attitude and the patients' approaches to the conversation

It is striking how the two patients have prepared differently and how the professional attunes differently. Patient 1 and his friend have written down nothing and the overall impression is that Patient 1 has made little effort to prepare for the conversation and has a rather nonchalant approach to it. But the nurse does not consider this to be disqualifying. In contrast, Patient 2 eagerly explains that he and his wife have "done as they were told": they "went through the booklet" and his wife has "written in it". He, thus, seems quite obedient and responsible. Unlike with Patient 1, however, the nurse does not say it is "quite OK", when it turns out the booklet has gone missing.

The difference in the two men's approaches to the conversation demonstrates their economically unequal positions: while Patient 2 is greatly dependent on free access to care and financial support, Patient 1 has the money to buy services he does not receive or is dissatisfied with. The implications of this are that Patient 1 holds an attitude of carefree superiority; he does not need to prepare properly, because he does not need to fear sanctions. By contrast, Patient 2 is very dependent on care and benefits, and seems to feel that he must cooperate and obey orders like writing "answers" in the booklet.

It is even more striking that the nurse introduces the patients to Aamann in quite different terms. Patient 1 is not described as problematic, although he seems less compliant than Patient 2, who is presented as having "problems with compliance" despite his eagerness to cooperate. The nurse also says that Patient 2 "only talks about" doing things, whereas it was quite acceptable for Patient 1 to lie on the sofa. We also see that the nurse trusts Patient 1 much more than Patient 2: she expresses full confidence in



Patient 1's ability to make the "right" choices, such as lying on the sofa on certain days. Conversely, there is doubt about Patient 2's ability to assess his own activity level.

According to Sointu (2017), clinicians' perceptions of patients draw from a repertoire of social stereotypes. For example, "good" patients are seen as active participants who are involved and motivated to "learn about their disease and take charge of it" (ibid., p. 68). In contrast, "bad" patients refuse "the responsibilities of the 'sick role" (ibid., p. 69); they resist doctors' recommendations and make bad choices. They neither take an active part in their healthcare nor do they communicate well (p. 70). These norms are present in our study, where it seems that the nurse considers Patient 1 a "good" patient and Patient 2 a "bad" patient.

Talking about death

Patient 2 receives a challenging question about turning off the pacemaker and the oxygen. It is worth noticing that the question is not in the booklet and that Patient 1 is not asked explicitly about his forthcoming death. This may be because Patient 2 is closer to death, but nevertheless it is thought-provoking that the question is posed in relation to important everyday things and life quality, where the nurse elaborates on the differences between the illnesses that Patient 2 and his wife are dealing with. This leaves an impression of a lack of compassion towards him. Patient 2 is, however, clearly reluctant to talk about death. Instead of reflecting on his wishes and worries, he becomes short of breath and states that he would rather not speculate on it.

Institutionalised terms such as "involvement" and "dialogue" very often presuppose a reflexive self, which is a class-based and, thus, unevenly distributed resource (typically acquired through education) (Skeggs et al. 2008; Aamann 2017; Sointu 2017). Howarth (2007, p. 425) discusses the problem of the need to participate actively in communication about one's death, because the main interest in this seems to come from better-off middle-class people. She argues that a form of stoic calm characterises working-class culture, which conflicts with the implicit perception that all end-of-life patients and their families need to articulate their suffering using the correct, self-reflexive terminology.

The problem is, thus that because the conversation indirectly requires the desire and ability to reflect upon and talk about death, Patient 2 is perceived as someone who may suffer from "poor illness insight"/have compliance problems. However, a conversation between a healthy professional at work and an ill person in a low position in society with a loss of previous social identity is asymmetrical per se, which can make equity difficult regardless of the professional's intention (Miczo 2003). Furthermore, Patient 2's fear of death might be an obstacle to professional procedures, because it may prevent identification and documentation of his "final wishes".

Different classes—different access to active ageing

The distinctions between good and bad patients are closely related to class inequality (Sointu 2017) and there are, thus, many people who are unable to be a "good" patient, performing a health-entrepreneurial, valuable self. As Liveng (2016) argues:



"When desirable old age is unambiguously presented as 'active', this conceals the fact that older people's possibilities to live up to its normative ideals are unevenly distributed" (p. 148; author's translation). According to Dumas and Laberge, "class dispositions towards physical activity manifest themselves during ageing" (Dumas and Laberge 2005, p. 186). They also note: "different classes enter ageing with different habitus. The working classes, for example, may be more disposed than the middle or upper classes to accept bodily decline as inevitable rather than to seek improvement in their bodies" (Dumas and Laberge 2005, p. 188).

In this perspective, Patient 2 may have an understanding of body and self that conflicts with the normative ideals, as he might have accepted the weakening of his body and, thus, finds it pointless to exercise. Further, he becomes confused and anxious when the staff come to his room with a range of activities. The same applies to Patient 1, at the opposite extreme: his habitus fits into the dominant narrative of being active and keeping the disease in check. The two men's previous work and life conditions are a point to consider here: Patient 1 was a businessman, while Patient 2 did hard manual work. Further, there is a marked difference in their financial basis for enterprise and optimisation. Patient 1 buys a garage for fun, while Patient 2 cannot afford reading glasses.

It is striking that the nurse seems unaware of these differences in terms of class. Arguably, instead of compensating for inequality, she is reproducing it by attributing different symbolic and moral value to the "good" and the "bad" patient. This can be attributed to neoliberal individualisation in which class inequalities are typically neglected and disadvantage is understood as a result of psychological deficits and moral deficiencies (Reay 2005).

Patient 1's driving around and chatting with people is valued as rehabilitation by the nurse. There may be good reason for this: Macdonald, whose field is dementia, points out that relationships are a vital aspect of dementia care, because "to live is to be held in connection" (Macdonald 2018, p. 290).

This obviously works for Patient 1, who is free to choose what he wants to do. He is also a busy man, rounding off the conversation because the cleaning is coming. He expresses a kind of moral superiority when he emphasises that he is not the type to complain about everything – subtly distinguishing himself from people who do complain. For Patient 1, it is quite natural to "keep going": his life is pleasant, with interesting hobbies, socialising and financial freedom. Conversely, Patient 2 is bedridden and has poor finances. Yet he expresses a strong desire to "be held in connection": his greatest hope is that the staff: "would just ask how I am. And maybe chat a bit". In contrast to Patient 1, however, Patient 2 finds that no one shows interest in him; they do not come when he calls.

Sointu noted: "Even when, formally, all patients receive the same care, informally, medical students observe good patients being afforded time, care and appreciation that bad patients are thought not to deserve or want" (2017, p. 71). In line with this, Patient 1 is offered help if he decides on publicly funded senior housing instead of buying a flat himself, although he would probably be able to manage by himself. Meanwhile, Patient 2 seems to be perceived as "undeserving" as he is judged as a "bad" and irresponsible patient; he needs welfare payments and does not make an active effort to keep going, but is then sanctioned.



Discussion

We have seen how the discourse of active ageing generates class-based distinctions between "good" and "bad" patients. We have shown how the ideal of old age intrudes into the healthcare system and thereby influences the handling of ageing and death, illustrating how active ageing permeates palliative care to create normative expectations with demands that many end-of-life patients might be unable to meet.

In line with Sointus' point about how clinicians' perceptions of patients draw from a repertoire of social stereotypes, a further important point is that healthcare professionals in Denmark also belong to the broad middle classes (Pedersen and Caspersen 2020, p. 8). Previous studies of Danish prevention policy show that clinicians' work is largely coloured by the professionals' personal tastes and preferences, based on their class (Harrits and Møller 2016; Aamann and Dybbroe 2018).

Furthermore, nurses are also subject to the neoliberal discourses of value accumulation by taking on the role of health entrepreneurs to enhance symbolic value. Since class is increasingly configured through the symbolic value of the self, it can be almost impossible not to adhere to the distinction between legitimate and illegitimate end-of-life patients. This hegemonic middle-class consciousness blocks awareness of class differences in the ability to comply with the norms of ageing.

This study has several limitations due to its methodological choices: it is a small study and, thus, not representative of Denmark as a whole, although it does include data from both a rural and an urban area. Furthermore, the patients were not subsequently interviewed about their palliative care experiences, and the professionals were not interviewed with a focus on class. There are several reasons for this: the perspectives presented in this article were only systematically analysed after the project had ended. Further, class is often perceived as illegitimate since it raises questions about moral worth. In qualitative interviews, therefore, informants are often evasive when class is mentioned explicitly (Aamann 2017; Popay et al. 2003). Skeggs argues that to speak about class is different from living it; people seldom consider themselves or their practices in terms of class. Unlike gender and ethnicity, which are often explicitly referred to, class works as a "structuring absence" (Skeggs 1997, p. 74). It is, thus, debatable whether interviewing the patients or the professionals would have further illuminated the processes explored here. However, interviewing healthcare professionals about social inequality might have clarified how the discourses, the culture and the institutional framework encourage them to adopt middle-class positions and praise active ageing in palliative care conversations.

Conclusion

In this article we have explored how discourses of active ageing establish new distinctions between "successful" and "irresponsible" agers and how this aligns with class as conceptualised by Bourdieu and Skeggs. We have shown how



classifying practices of value attribution shape palliative encounters. We have analysed two cases and revealed how the quality of palliative care varies even when the service provided is identical; privileged Patient 1 is supported through acknowledgements and is, thus, approached as a subject of value, i.e. a "good" patient, while disadvantaged Patient 2 is met with a form of indulgent patience and dignity violations, since he is a "bad" patient.

It is particularly interesting that class is reinforced in palliative care in a universal welfare state with equal rights to publicly funded healthcare. It is notable that Patient 1, who is supported by his wealth, is assumed to need help and receives it, while Patient 2, who needs greater social, financial and health-related support, is allocated a lower level of service.

We can, thus, conclude that palliative care is unequally distributed along class lines, and appears to be yet another good for well-situated privileged patients, who already reap the most benefits from healthcare in the Nordic welfare states.

If social class plays no part in our understanding of differences in health professionals' ways of interacting with ageing and dying people, there is a significant risk of reproducing such socially differentiated practices.

Several quantitative studies have described this differentiation, but without explaining why and how it takes place. In this qualitative study, our particular aim was to understand how the notion of active ageing becomes a horizon for palliative care which obscures an understanding of the importance of social class in palliative practices. The analysis, therefore, reveals how inequality in palliative care takes place, unnoticed by healthcare systems, professionals and quantitative research.

Unequal health is not mainly created in the healthcare system, as it is a consequence of inequality in society. But in order to achieve equity, it is crucial to address the socially unequal situation of patients. We, therefore, suggest improving the quality and sensitivity of medical training. This could help mitigate some of the negative effects of class highlighted in this article, such as the reliance on stereotypes when providing patient care.

Funding Open access funding provided by Roskilde University.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/.

References

Aamann, I.C. 2020. Neoliberalism, healthism and moral judgements: A psychosocial approach to class. *Journal of Psychosocial Studies* 13 (3): 319–332.



- Aamann, I.C., and B. Dybbroe. 2018. 'So under "cause for concern", I' 'll write that ...' class, parenting and risk prevention in public health practices in schools: A question of moral value? *Health, Risk & Society* 20 (5–6): 259–275.
- Aamann, I.C., and M. Erlik. 2023. "Am I that bad?" Middle-class moralism and weight stigma towards parents of children with higher weight. *Children & Society*. https://doi.org/10.1111/chso.12779.
- Aamann, I.C., and B.R. Olesen. 2020. Marginalized citizens experiences of middle class moral judgements in communication with their GPs. Socialmedicinsk Tidskrift 3: 442–453.
- Aamann, I.C. 2017. "Oh! Iben is here now, so we better behave properly"—the production of class as morality in research encounters. Forum Qualitative Sozialforschung/Forum: Qualitative Social Research 18(3): art. 7.
- Andersen, J.G., N. Ploug, L. Andersen, L. Olsen, and S. Caspersen. 2021. Rige b\u00farn leger bedst. Et portræt af det danske klassesamfund [Rich kids play together. A portrait of Danish class society]. Copenhagen: Gyldendal.
- Behandlingsrådet. 2023. Behandlingsrådets rapport vedrørende ulighed i somatisk behandling af patienter med psykiske lidelser [Report by the Danish Health Technology Council on inequality in physical healthcare of mental health patients]. Aalborg: Aalborg University.
- Bourdieu, P. 1990. The logic of practice. Stanford: Stanford University Press.
- Bourdieu, P. 2010. Distinction: A social critique of the judgement of taste. Cambridge: Harvard University Press.
- Bourdieu, P., A. Accardo, G. Balazs, S. Beaud, F. Bonvin, E. Bourdieu, P. Bourgois, S. Broccolichi, P. Champagne, R. Christin, J.P. Faguer, S. Garcia, R. Lenoir, and F. Ceuvrard. 1999. *The weight of the world: Social suffering in contemporary society*. Cambridge: Polity Press.
- Bourdieu, P., and J.C. Passeron. 2006. *Reproduktionen* [Reproduction in Education, Society and Culture]. Copenhagen: Hans Reitzels Forlag.
- Carter, C., S. Mohammed, R. Upshur, and P. Kontos. 2020. Biomedicalization of end-of-life conversations with medically frail older adults—Malleable and senescent bodies. *Social Science and Medicine*. https://doi.org/10.1016/j.socscimed.2020.113428.
- Caspersen, S. 2021. *I det rigeste lokalområde tjener de fem gange mere end bunden* [In the richest local community, people earn five times more than in the one at the bottom]. Copenhagen: Arbejderbevægelsens Erhvervsråd/The Economic Council of the Labour Movement.
- Clark, D. 1999. 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958–1967. Social Science and Medicine 49 (6): 727–736.
- Conway, S. 2013. Representing dying, representing class? Social distinction, aestheticisation and the performing self. *Mortality* 18 (4): 327–338. https://doi.org/10.1080/13576275.2013.850470.
- Crawshaw, P. 2012. Governing at a distance: Social marketing and the (bio)politics of responsibility. *Social Science and Medicine* 75 (1): 200–207. https://doi.org/10.1016/j.socscimed.2012.02.040.
- Davies, C.A. 1999. Reflexive ethnography. A guide to researching selves and others. London: Routledge.
- Davis, C. 2015. Drugs, cancer and end-of-life care: A case study of pharmaceuticalization? *Social Science and Medicine* 131: 207–214. https://doi.org/10.1016/j.socscimed_2014.12.007.
- Diderichsen, F., I. Andersen, and C. Manuel. 2011. *Ulighed i sundhed—Årsager og indsatser [Health inequality: Causes and measures]*. Copenhagen: Sundhedsstyrelsen/The Danish Health Authority.
- Dumas, A., and S. Laberge. 2005. Social class and ageing bodies: Understanding physical activity in later life. *Social Theory and Health* 3 (3): 183–205. https://doi.org/10.1057/palgrave.sth.8700056.
- Faber, S.T., A. Prieur, L. Rosenlund, and J. Skjøtt-Larsen. 2012. *Det skjulte klassesamfund* [The hidden class society]. Aarhus: Aarhus University Press.
- Fetterman, D.M. 2018. (2018) Empowerment evaluation's roots in community. *New Directions for Evaluation* 157: 87–88. https://doi.org/10.1002/ev.20289.
- Flyvbjerg, B. 2006. Five misunderstandings about case-study research. *Qualitative Inquiry* 12 (2): 219–245.
- Gilleard, C., and P. Higgs. 2011. Ageing abjection and embodiment in the fourth age. *Journal of Aging Studies* 25 (2): 135–142. https://doi.org/10.1016/j.jaging.2010.08.018.
- Harris, R., C.N. Wathen, J.C.D. Macgregor, S. Dennhardt, A. Naimi, and K.S. Ellis. 2016. "Blaming the flowers for wilting": Idealized aging in a health charity video. *Qualitative Health Research* 26 (3): 377–386. https://doi.org/10.1177/1049732315570121.
- Harrits, G.S., and M.Ø. Møller. 2016. Forebyggelse og bekymring i professionel praksis [Prevention and concern in professional practice]. Copenhagen: Hans Reitzels Forlag.



- Howarth, G. 2007. Whatever happened to social class? An examination of the neglect of working class cultures in the sociology of death. *Health Sociology Review* 16 (5): 425–435. https://doi.org/10.5172/hesr.2007.16.5.425.
- Katz, S. 2000. Busy bodies: Activity, aging, and the management of everyday life. *Journal of Aging Studies* 14 (2): 135–152. https://doi.org/10.1016/S0890-4065(00)80008-0.
- Lamont, M. 2012. Toward a comparative sociology of valuation and evaluation. Annual Review of Sociology 38 (1): 201–221.
- Lawler, S. 2005. Disgusted subjects: The making of middle-class identities. *The Sociological Review* 53 (3): 429–446.
- Liveng, A. (2016) Aktiv aldring—en sundhedsskabende eller usynliggørende diskurs? [Active ageing: A discourse to promote health or to make people invisible?] In *Ulighed i sundhed: Nye humanistiske og samfundsvidenskabelige perspektiver* [Health inequalities: New perspectives from the humanities and social sciences], ed. S. Christiansen et al., 147–174. Frederiksberg: Frydenlund Academic.
- Macdonald, G. 2018. Death in life or life in death? *Dementia's Ontological Challenge. Death Studies* 42 (5): 290–297. https://doi.org/10.1080/07481187.2017.1396398.
- Madison, S. 2004. Introduction to critical ethnography. In Critical ethnography, methods, ethics, and performance, ed. S. Madison, 1–17. Los Angeles: Sage.
- Marcus, G.E. 1995. Ethnography in/of the world system: The emergence of multi-sited ethnography. Annual Review of Anthropology 24 (1): 95–117. https://doi.org/10.1146/annurev.an.24.100195. 000523.
- May, P., and J.B. Cassel. 2018. Economic outcomes in palliative and end-of-life care: Current state of affairs. Annals of Cardiothoracic Surgery 7 (Suppl 3): S244–S248. https://doi.org/10.21037/apm. 2018.06.06.
- McCreaddie, M. 2011. Communication, information, and support. In *Death, dying, and social differences*, ed. D. Oliviere, B. Monroe, and S. Payne, 45–56. Oxford: Oxford University Press.
- McLaren, P. 2005. Critical pedagogy and class struggle in the age of neoliberal terror. *Revista Internacional De Educacion Para La Justicia Social* 4 (2): 29–66.
- Miczo, N. 2003. Beyond the "fetishism of words": Considerations on the use of the interview to gather chronic illness narratives. *Qualitative Health Research* 13 (4): 469–490. https://doi.org/10.1177/ 1049732302250756.
- Olesen, B.R., L.J. Phillips, and T.R. Johansen, eds.2018. *Dialog og samskabelse—Metoder til en reflek-siv praksis* [Dialogue and co-creation: Methods for reflective practice]. Copenhagen: Akademisk Forlag.
- Olson, R.E., A. Smith, P. Good, E. Neate, C. Hughes, and J. Hardy. 2020. Emotionally reflexive labour in end-of-life communication. *Social Science and Medicine* 112928: 1–9. https://doi.org/10.1016/j.socscimed.2020.112928.
- Pedersen, L.H., F. Erdmann, G.L. Aalborg, L.L. Hjalgrim, H.B. Larsen, K. Schmiegelow, J.F. Winther, and S.O. Dalton. 2021. Socioeconomic position and prediagnostic health care contacts in children with cancer in Denmark: a nationwide register study. *BMC Cancer*. https://doi.org/10.1186/s12885-021-08837-x.
- Pedersen, S.T., and S. Caspersen. 2020. *Din klasse følger dig gennem livet* [Your class follows you throughout life]. Copenhagen: Arbejderbevægelsens Erhvervsråd/The Economic Council of the Labour Movement.
- Phillips, L., and M. Scheffmann-Petersen. 2020. Unpacking "patient-centredness": How knowledge is negotiated dialogically in the interweaving of genres and voices in counselling conversations. *Sociology of Health and Illness* 42 (6): 1456–1472. https://doi.org/10.1111/1467-9566.13118.
- Popay, J., et al. 2003. Beyond "beer, fags, egg and chips"? Exploring lay understandings of social inequalities in health. *Sociology of Health and Illness* 25 (1): 1–23.
- Pors, A.S. 2014. Hospitalets strategiske patientkommunikation—styring af sundhedsprofessionel praksis? [The hospital's strategic patient communication: Governing health professional practice?]. Tidsskrift for Arbejdsliv 16 (1): 11–24.
- Reay, D. 1997. Feminist theory, habitus, and social class: Disrupting notions of classlessness. *Women's Studies International Forum* 20 (2): 225–233.
- Reay, D. 2005. Beyond consciousness? The psychic landscape of social class. *Sociology* 39 (5): 911–928. Richards, N. 2022. The equity turn in palliative and end of life care research: Lessons from the poverty literature. *Sociology Compass* 16 (5): 1–15. https://doi.org/10.1111/soc4.12969.
- Rigsrevisionen. 2019. Forskelle i behandlingskvaliteten på sygehusene [Differences in treatment quality in hospitals]. Copenhagen: Rigsrevisionen/Danish National Audit Office.



- Rose, N. 1990. Governing the soul: The shaping of the private self. London: Routledge.
- Skeggs, B. 1997. Formations of class and gender: Becoming respectable. London: SAGE.
- Skeggs, B. 2005. The making of class and gender through visualizing moral subject formation. *Sociology* 39 (5): 965–982.
- Skeggs, B. 2014. Values beyond value? Is anything beyond the logic of capital? *The British Journal of Sociology* 65 (1): 1–20.
- Skeggs, B., H. Wood, and N. Thumin. 2008. "Oh goodness, I am watching 'reality' television": How methods make class in audience research. European Journal of Cultural Studies 11 (1): 5–24.
- Sointu, E. 2017. 'Good' patient/'bad' patient: Clinical learning and the entrenching of inequality. *Sociology of Health and Illness* 39 (1): 63–77. https://doi.org/10.1111/1467-9566.12487.
- Sundhedsstyrelsen. 2017. Anbefalinger for den palliative indsats [Recommendations for palliative care]. Copenhagen: Sundhedsstyrelsen/The Danish Health Authority.
- Thagaard, T. 1998. *Systematikk og innlevelse—En innføring i kvalitativ metode* [Systematic thinking and insight: An introduction to qualitative methods]. Bergen: Fagbokforlaget.
- Tjørnhøj-Thomsen, T., and H.P. Hansen. 2009. Overskridelsens etik. Erfaring, analyse og repræsentation [The ethics of transgression. Experience, analysis and representation]. In *Mellem mennesker—En grundbog i antropologisk forskningsetik* [Between people: An introduction to anthropological research ethics], ed. K. Hastrup, 223–248. Copenhagen: Hans Reitzel.
- Türken, S., H.E. Nafstad, R.M. Blakar, and K. Roen. 2015. Making sense of neoliberal subjectivity: A discourse analysis of media language on self-development. *Globalizations* 13 (1): 1–15.
- Tyler, I. 2015. Classificatory struggles: Class, culture and inequality in neoliberal times. *Sociological Review* 63 (2): 493–511. https://doi.org/10.1111/1467-954X.12296.
- Udesen, C.H., et al. 2020. *Social ulighed i sundhed og sygdom* [Social inequality in health and illness]. Copenhagen: Sundhedsstyrelsen/The Danish Health Authority.
- Walkerdine, V. 2003. Reclassifying upward mobility: Femininity and the neo-liberal subject. *Gender and Education* 15 (3): 237–248.
- Wiersma, M., et al. 2019. "Treat them into the grave": Cancer physicians' attitudes towards the use of high-cost cancer medicines at the end of life. *Sociology of Health and Illness* 41 (2): 343–359. https://doi.org/10.1111/1467-9566.12830.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

