

**The discursive construction of person-centredness in online information leaflets addressed to patients with cancer**

Ottesen, Aase Marie; Strunck, Jeanne

*Published in:*  
Qualitative Health Communication

*DOI (link to publication from Publisher):*  
[10.7146/qhc.136743](https://doi.org/10.7146/qhc.136743)

*Creative Commons License*  
CC BY-NC 4.0

*Publication date:*  
2024

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

[Link to publication from Aalborg University](#)

*Citation for published version (APA):*  
Ottesen, A. M., & Strunck, J. (2024). The discursive construction of person-centredness in online information leaflets addressed to patients with cancer. *Qualitative Health Communication*, 3(1).  
<https://doi.org/10.7146/qhc.136743>

**General rights**

Copyright 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 us at [vbn@aub.aau.dk](mailto:vbn@aub.aau.dk) providing details, and we will remove access to the work immediately and investigate your claim.



QUALITATIVE HEALTH COMMUNICATION  
VOLUME 2, ISSUE 2, 2023  
ISSN: 2597-1417

# The discursive construction of person-centredness in online information leaflets addressed to patients with cancer

Aase Marie Ottesen<sup>1</sup>

Jeanne Strunck<sup>2</sup>

**NAME OF DEPARTMENTS AND INSTITUTIONS:**

<sup>1</sup> Department of Communication and Psychology, Aalborg University, Denmark

<sup>2</sup> Department of Culture and Learning, Aalborg University, Denmark

**CORRESPONDING AUTHOR:**

Aase Marie Ottesen. E-mail: [aamo@ikp.aau.dk](mailto:aamo@ikp.aau.dk)

---

## ABSTRACT

**Background:** This article is part of a project that examines the discursive constructions of the concepts, 'patient' and 'patient identity' in documents regarding national laws and steering documents, as well as regional steering documents, and how these constructions appear in online patient information leaflets. **Aim:** The focus of the article is whether person-centredness as an approach to the patient is prevalent in the discourses found in regional online materials for cancer patients in Denmark. **Methods:** The study uses a mixed method approach analysing the data within a critical discourse analytical framework, combined with quantitative analyses conducted using the corpus analysis software program, AntConc. **Results:** The present study reveals that the patient's scope of action is most often limited in patient information leaflets. Patients are positioned as objects for the actions of the healthcare staff even though different constructions of person-centredness are present. **Discussion:** A person-centred culture must also be present in the way the professional staff and management communicate and cooperate. **Conclusions:** As a layperson and object, the patient is given an identity as a medical case, not as an involved and actively participating person. There are only minor signs of a person-centred approach.

## KEYWORDS

Cancer patients, discourse analysis, healthcare system, information leaflets, person-centredness

## BIOGRAPHIES

**Aase Marie Ottesen**, PhD, Master in Humanities and Health Studies (MHH), RN. Guest researcher at Department of Communication and Psychology, Aalborg University. Her focus in research is dementia, user involvement, relational communication and coordination, interdisciplinary collaboration, learning and patients' access to equal care and health.

E-mail: aamo@ikp.aau.dk. ORCID: 0000-0002-5671-6759.

**Jeanne Strunck**, PhD, Emeritus Associate Professor at the Department of Culture and Learning at Aalborg University, Denmark. Her main research areas include intercultural communication in organizations, rhetoric, discourse and gender, discourse and leadership, discourse and health communication.

E-mail: strunck@ikl.aau.dk. ORCID: 0000-0003-4662-6837.

## Introduction

This article examines person-centredness as an approach to the patient in regional online information leaflets for patients enrolled in cancer patient pathways and in medical treatment for cancer in Denmark. The cancer patient pathway means that hospitals throughout the country all work from the same professional healthcare guidelines. Every patient pathway has a stated objective as to the period allowed from the time a patient is referred to diagnostic services until the patient is in treatment. This period of time has been determined nationally, regulated according to a national Act (Sundheds- og Ældreministeriet, 2015), but differs according to the type of cancer.

The Danish healthcare system comprises several levels, each with their own areas of function, based on existing legislation, politically determined by Folketinget, the Danish parliament (Folketinget, 2020). On the political level, The Ministry of the Interior and Health is responsible for the Danish healthcare system. The Ministry of Health is assisted by the Danish Health Authority, which is the highest authority of healthcare in Denmark (Sundhedsstyrelsen, 2020). The State constitutes the highest level and is responsible for the overarching framework, planning and management, which includes the area of health. The next level consists of 98 municipalities and five Regions, which are responsible for the implementation of the adopted laws, regulations, and codes of practice in relation to patients (Indenrigs - og Sundhedsministeriet, 2005). As a part of the public health sector's efforts regarding health and disease, the national, regional, and municipal actors disseminate information leaflets online that are accessible to all. This article focuses on online information leaflets published by one of the five regions in Denmark: the Region of Northern Jutland, represented by the largest hospital in the region, Aalborg University Hospital.

The study focuses on the discursive construction of the patient in the data and whether person-centredness prevails in the discourses, or whether discourses found in earlier studies of Danish healthcare legislation and national quality development programmes (Lassen et al., 2015; Lassen et al., 2018) may be found in the data. These earlier studies of health legislation (Lassen et al., 2015; Lassen et al., 2018) show that, since the 1980s, the welfare discourse that traditionally characterised the Danish healthcare system has been influenced by a New Public Management discourse. Governing the Danish welfare system in line with New Public Management resulted in changes into a more neoliberal approach to public healthcare with an emphasis on individual agency, autonomy, and freedom of choice. Private health facilities have emerged as part of the services offered, and the role of patient becomes the role of customer (Jensen 2011).

The discursive constructions in the documents revealed, however, that the patient's scope of action, here meant as the possibility and power to act, is limited, as the greater scope of action is still delegated to healthcare staff (Lassen et al., 2015).

The problems and complexes emerging from the analysis of the healthcare legislation and national quality development programmes are taken further in the present study by analysis of how and whether the discursive constructions of the documents are applied to or have changed in the information leaflets addressed to patients. With this intention, we examine person-centredness as an approach to the patient in regional online information leaflets for

patients enrolled in 'cancer patient pathways' and in medical treatment for cancer. Such analyses may reveal the degree to which political intentions of person-centredness, agency and involvement of patients are implemented in texts and practice and facilitate person-centredness.

In relation to the above-mentioned intentions of person-centredness, we want to investigate the following overarching research question in the present study:

- How are the discursive constructions of the patient in online patient information leaflets compatible with results from earlier studies and how does person-centredness prevail in the discourses?

For this purpose, we address the following sub-questions:

- How is the patient discursively constructed?
- What is the scope of action assigned to the patient?
- Which discourses are dominant?
- Are the discursive constructions characterised by a person-centred approach to the patient and if so, how do they appear and how are they expressed?

## Literature review

### Person-centred approach

The person-centred approach has been a part of strategies, visions and goals in the healthcare system, in Denmark and internationally for many years (Forskningsenhed for Klinisk Sygepleje Aalborg Universitetshospital et al., 2019; Kitson et al. 2012a, 2013b). Despite this, there is no agreed upon definition of the concept. This lack of consensus not only pertains to the definition of the concept, but also to its essential elements, the best practice, and how to measure the outcome of a person-centred approach in health services (Brummel-Smith et al., 2016; McCormack et al., 2015). Related to the concept 'person-centeredness' is 'patient-centeredness' which, as well as person-centeredness, "prioritizes the needs and experiences of the patient as a person" (Fage-Butler, 2013, p. 107). However, in the present article, we have chosen person-centeredness as the approach because according to Travelbee (1966), the concept of 'patient' is a generalization that undermines the person's individuality. Furthermore, patient-centeredness restricts the view on the person and may be stigmatizing in regard to identity. 'Person-centeredness' covers a broader and more inclusive view on the person (Lassen et al., 2015; Olesen, 2007).

In "Framework on integrated, people-centred health services" from 2016, the World Health Organisation (WHO) presents their vision of people-centred health services, stating that all people should have equal access to high quality health services that are designed and implemented in a way that meets the needs of the individual in their present life situation. Health services should be coordinated across the continuum of care and services and should be offered in a safe, effective, timely and acceptable way (WHO, 2016). Furthermore, WHO describes how they understand people-centred care. It is an approach to care that consciously includes the individual, the caretakers, the families and communities as participants in and

beneficiaries of trustworthy health services that are organized around the individual's needs as a whole, rather than diseases, and where the individual's social preferences are respected. People-centred care requires furthermore that patients have the education and receive the support they need, in order to make decisions and participate in their own care.

Based on a comprehensive literature review and interviews with representatives from nine different areas in the healthcare sector, the American Geriatrics Society Expert Panel on Person-Centered Care (Brummel-Smith et al., 2016) developed a definition of person-centred care and identified essential elements that must be present in order to realise person-centred care in practice. The panel's definition states that in person-centred care, the values and preferences of the individual are the basis for setting realistic goals and care planning in a dynamic relationship and collaboration between the patient, family and healthcare professionals. The panel defines essential elements that are necessary for realising person-centred care in practice, including the creation of an individualized, goal-oriented care plan based on the person's preferences. The achievement of the person's goals and plan, the continuous information sharing, and integrated communication should be reviewed and evaluated to assure that the person is heard. The communication should be open between the person and everyone involved in their care and treatment, and there should be active coordination between all involved healthcare professionals (Brummel-Smith et al., 2016).

In the context of Danish healthcare, the Danish Health Authority (Sundhedsstyrelsen, 2019) describes person-centred care as a fundamental approach for all people who need support and care. First and foremost, it is about seeing the other person as a unique individual: as a person who should be acknowledged and respected, and who has their own life story and personality (Sundhedsstyrelsen, 2019, p. 6).

Since 2012, Denmark has participated in an international collaboration regarding development of a conceptual framework for nursing called Fundamentals of Care. Aalborg University and Aalborg University Hospital, whose online information leaflets are the focus of this study, are represented in this collaboration. Fundamentals of Care is to be understood as person-centred nursing with a focus on continuity and professional quality. This international collaboration was established in 2008 within the framework of International Learning Collaborative (ILC) led by professor and nurse Alison Kitson in Adelaide, Australia. The Region of Northern Jutland is represented in the international collaboration by six institutions that have played an important role in implementing the conceptual framework of Fundamentals of Care, and thus person-centred nursing, into the planning and completion of clinical nursing and education, teaching, management, development and research in clinical nursing. The focus of the conceptual framework is how the patient and nurse, in a safe and competent atmosphere, may mutually evaluate the patient's need for care, create a joint care plan, follow, monitor and adjust this plan towards evaluation and completion of the intervention (Forskningsenhed for Klinisk Sygepleje et al., 2019).

In these definitions of person-centred care and illustrations of ways in which the person-centred approach can and should be practised, it is clear that they all are based on the same line of thinking and basic values. The values embedded in these definitions are that each person is unique, and values such as respect, dignity, equality, security, safety, mutual decision-making and planning are included, with respect for the individual's needs and preferences. However, an autonomous person able to govern their life and make adequate decisions and plans may be unable to do so in situations of serious illness (Beauchamp &

Childress, 2001). Bredenoord (2018) states that persons making their own decisions, living according to their values and beliefs are normally believed to live a good life, because they are granted the liberty to act in accordance with their autonomy and that “This is even more important when it concerns personal and identity determining decisions, which is often the case in healthcare” (Bredenoord, 2018, p. 136).

## Data and methodology

### Data

The total data set included in the study consists of 231 texts (Region Nordjylland, 2020; Onkologisk Afdeling, Aalborg Universitetshospital, 2020). The first reading of the 231 texts showed that 1) 204 texts constitute a separate set of texts from the Department of Oncology, including information to patients on medical treatment for cancer and monitoring for most types of cancer (Onkologisk Afdeling, Aalborg Universitetshospital, 2020) and 2) the remaining 27 texts are about cancer patient pathways (Region Nordjylland, 2020).

The information leaflets from the Department of Oncology about medical treatment and monitoring of patients include 14 themes (Onkologisk Afdeling, Aalborg Universitetshospital, 2020). In order to cover all texts meant for patients within the field of oncology, we choose to include both groups of texts. A general review of the texts was undertaken manually, resulting in further selection due to duplicates of some of the topics and the appearance of texts similar in structure as well as content. For the present study, texts were selected that were exemplary for the topics (Baker et al., 2008). In addition, a review of the texts suggested divergences among them, as some of the texts are purely informative, while others contain directive aspects as well. In the detailed analysis of the data material, we used this classification, and 27 texts were selected from each group (see Table 1 for an overview of data).

The 27 texts about cancer patient pathways (Region Nordjylland, 2020) contained both information and directive aspects and were divided into:

- Type A: 19 texts that have a uniform composition and structure. The information leaflets all have the following senders: Danish Regions, the Danish Health Authority, the Ministry of Health and Prevention, the Danish College of General Practitioners and Sundhed.dk (public website about health).
- Type B: 8 texts that contain, aside from a front page with a heading referring to the specific type of cancer, a page with a graphic illustration of the patient pathway with explanatory sub-headings and text parts as well as several links for further information. The information leaflets all have the Danish Health Authority as sender.

From each of the two types A and B, we selected one exemplary text because the texts are alike in structure and content: From type A, we selected a leaflet about cancer of the bladder and kidneys, and from type B, we selected a leaflet about breast cancer (see Table 1 for an overview of the data).

Table 1: Overview of data

Information materials/ category/number of selected texts	No. of texts	No. of texts of Type A and Type B		No. of selected texts		No. of selected text in each category	
		Type A	Type B	Type A	Type B	Informative aspects	Informative and directive aspects
Cancer patient pathways	27	19	8	1	1		
Medical treatment and monitoring of patients with cancer	204					27	27
Diarrhea and constipation						0	2
Good advice						4	13
Immunotherapy						1	0
Surgery						0	2
Chemotherapy						3	0
Diet and loss of appetite						1	4
Nausea and vomiting						5	0
Palliative treatment						1	0
Medicine						3	0
Scanning						0	2
Radiation therapy						5	1
Targeted treatment						0	0
Training and other services						1	1
Other, oncology						3	2
Total no. of texts	231	19	8	1	1	27	27

## Method

Based on a social constructivist perspective, where discourse is constituted by and constitutes social practice, this article has its starting point in sociocultural conditions arising out of governance mechanisms in the health sector, including traditional welfare ideology as well as development of the ideas of New Public Management. From a Foucauldian perspective, discourses are culturally constructed representations of reality, and they define the positioning of subjects (Arribas-Ayllon & Walkerdine, 2008). Discourses may create meaning in specific contexts and may reveal scopes of action, subject positions, and power relations in the text. For the analysis of data, this underlying approach is combined with Fairclough's critical discourse analysis (Fairclough, 1995; Fairclough 2003) as well as the approach of person-centredness. Inspired by Foucault and Fairclough, the analysis includes the dimension of text in describing the linguistic properties of the texts, the discursive practice in interpreting the relations between actors, texts and discourses and the sociocultural practice in explaining the texts in relation to the sociocultural conditions of the welfare state and New Public Management.

In the analysis, we apply mixed methods (Creswell, 2009), combining a qualitative and a quantitative approach. The qualitative discourse analyses are complemented by quantitative analyses conducted using the corpus analysis software programme AntConc (Anthony, 2020).

The corpus analyses were applied to find the 'quantitative fingerprint and the aboutness' of the language in the texts (Aasen et al., 2020), that is the use of pronouns for sender, recipient and the words most frequently used regarding the texts' actors. The incidence of these may, together with verbal forms and modality, reveal the discursive construction of actors, scopes of action and subject positions, as well as the possible presence of person-centredness.

### **Analytical approach**

The 54 information leaflets from the Department of Oncology about medical treatment and monitoring of patients were examined quantitatively, using corpus analysis. After that, exemplary texts were analysed qualitatively. As the 27 texts about cancer patient pathways were relatively few in number and manageable, they were first read thoroughly manually and relevant findings were noted, after which exemplary texts were chosen for detailed qualitative analysis.

After the corpus analysis and manual review of data, exemplary texts from each group were analysed qualitatively, inspired by critical discourse analysis. First, the qualitative analyses involved the online texts' distinctive characteristics and structures regarding purpose. After this, the discursive constructions of agency, the role of actor and scope of action were investigated, in which the use of pronouns, semantic word choice and incidence of deontic and epistemic modality (must, should, can, may, could) were paramount. However, differences between Danish and English wording and word order give rise to problems when wanting to make verbatim translations, specifically in relation to deontic and epistemic modality. Consequently, it was necessary to gather examples of the Danish 'can you / must you' and 'you can / you must' in boxes with the English word order in the table overviews from the AntConc analyses. As regards the Danish verb 'skal', we have chosen to translate it into 'must' as we find that 'must' clarifies the Danish deontic meaning. The final part of the analysis deals with the texts' discourses and the representation of person-centredness in the data.

## **Results**

The following results are divided into two dimensions: the first dimension regards the findings from the present study and the second dimension deals with the investigation of whether the discursive constructions of the patient in online patient information leaflets are compatible with results from earlier studies and how person-centredness prevails in the discourses.

### **Dimension 1: Findings from the present study**

The following findings are divided into two subsections: 1) Agency, actors and scope of action and 2) Discourses. First, each of the two subsections presents analyses of texts from cancer

patient pathways, and then analyses of information leaflets on medical treatment and monitoring of patients from the Department of Oncology.

### *Agents, actors, scope of action and subject positions*

#### Cancer patient pathways

A brief introduction to the texts explaining what a cancer patient pathway is uses a closeness strategy and the recipient is addressed by the pronoun 'you'. The start of the description of the pathway is constructed as meeting the needs the recipient might have, but the texts of type A do not directly address the patient, who is referred to as 'patients'/'the patient'. The patient is the object for actions done by the healthcare staff, who are implicitly the agents for the passive verbal forms. Only one professional (the doctor) is mentioned explicitly and positioned as the competent actor: "If surgery is performed, the removed tissue will be examined, so that the doctor can determine whether there is a need for further treatment". The texts are characterised by being impersonal, by the use of passive verbs and by epistemic modality that gives the healthcare staff opportunities to act: "This can be medical treatment in the form of immunotherapy". The noticeable use of the passive form and impersonal constructions precludes the presence of any other actors than the doctor, but other healthcare staff are given an implicit scope of action and an identity as professionally competent, in contrast to the patient. As a layperson and object, the patient is given an identity as a medical case, not positioned as an involved and actively participating person. There is no emphasis on person-centredness as seen in the values expressed by WHO (2016), Kitson (2013a, 2013b) and Fundamentals of Care (2019).

Regarding the texts of type B, the recipient is addressed consistently as 'you' in the whole leaflet and the designation 'patient' or 'patients' is only on the first page. Even though the recipient is constructed as a subject for a few active verbs, it appears that agency is owned by the healthcare staff: "If the tests show that you have cancer, you will continue on the cancer patient pathway, and you will be offered treatment". The recipient is only given a specific scope of action for contact and information: "Tell the staff how you feel, so that they can help you in the best possible way". In the texts, there are examples of deontic modality that demand commitment from recipient as well as healthcare staff: "If you haven't heard ... you must...", and of epistemic modality implying possibility and insecurity: "During treatment you may need alleviation, rehabilitation or other kinds of support".

Despite the fact that the recipient is not given the primary scope of action in the texts and is not positioned as a competent actor, there is emphasis in these information leaflets on involving the recipient and their family. Therefore, there is a certain degree of person-centredness, seen as participation in decision-making, respect, patient involvement and involvement of others than the person themselves, which is particularly seen in the section: "How do you wish to be involved?":

[...] Tell the hospital unit how you want to be involved, and whether you need help in making decisions. Or whether you need more time to talk about your situation with your family. [...]. The best results are achieved when decisions are made in collaboration between you and the healthcare staff. (Region Nordjylland, 2020, p.3)

## Information leaflets on medical treatment and monitoring of patients

Table 2 shows the most frequently used vocabulary that can contribute to revealing the discursive construction of actors and scopes of action.

*Table 2: Incidence of vocabulary in information leaflets on medical treatment and monitoring of patients, Department of Oncology, divided into purely informative texts and texts containing informative and directive aspects.*

Focus points on quantitative text analysis		Purely informative texts	Text containing informative and directive aspects
No. of texts		27	27
No. of words		20.902	14.196
Personal pronoun (recipient)	You (subject)	746	571
	You (object)	161	87
	Your	190	108
Personal pronoun (sender)	We	85	70
	Us	47	40
Actors	Doctor/the doctor/specialist	59	13
	General practitioner	6	0
	Nurse/the nurse	15	6
	District nurse/home carer	3	4
	Other professionals (i.e., physiotherapist, dietician)	18	8
	Partner/family/other close relatives	34	9
	Patient/patients/the patient/cancer patients	54	2
	Person	8	0
Modal verbs	Can / may	471	292
	Must	172	97
Patient's scope of action	You can / may	138	114
	You must	109	64
Imperatives	Use	30	39
	Avoid	29	59
	Be	24	13
	Remember	8	8

In the purely informative texts, the patient is given an identity as a medical case, positioned as an object and recipient of services and treatment determined by the healthcare system. This is underlined by the fact that in the quantitative count of words used (Table 2), there is frequent use of the words: 'patient', 'patients', 'the patient' or 'cancer patients' (54 times). The words 'doctor', 'the doctor', 'the specialist' also occur frequently (59 times), as well as other professionals such as 'nurse' and 'physiotherapist' (36 times). In the texts, it appears that agency and scope of action are the province of the healthcare professionals because of their professional authorisation and competence. The use of personal pronouns reinforces the sender as an actor and the patient as a passive recipient of the healthcare services: "... therefore we monitor your blood tests", "we assess..." ('we' is used 85 times). In the texts, the recipient is addressed by the pronoun 'you' and, as seen in Table 2, 'you' is used a total of 746 times in the texts. This could reflect a person-centred approach, but this is not the evident picture. On the contrary, when 'you' appears together with the frequently used deontic modal

verb 'must' (172 times), the patient becomes the object of the actions, e.g.: "During phase 2 you will have to receive radiation therapy", or they are required to act in certain ways: "If you vomit, you must....".

When 'you' is combined with the epistemic modal verb 'can', which appears 471 times in the text, a certain scope of action is delegated to the patient, which opens the possibility of choice. This is most often the case when ways to alleviate discomfort are described, e.g.: "you can alleviate this by...", and "you can prevent....".

In the texts containing information and directive aspects, the words 'patient' or 'cancer patient' appear only twice, and the words 'doctor', 'the specialist' (13 times) and other professionals such as 'nurse' (18 times) appear considerably less than in the purely informative texts (Table 2). However, agency and a larger scope of action are assigned to the healthcare professionals, and the patient is given an identity as a medical case and positioned as an object and recipient of services.

As in the purely informative texts, the patient is given agency and a specific scope of action in the action-oriented texts, which is seen clearly in the use of 'you can' (appears 114 times). Compared to the purely informative texts, the action-oriented texts are, however, most often followed by specific advice about what the patient can do. Here, imperatives are used to make the advice clear, for example in the text about alleviating discomfort caused by radiation therapy: "You can alleviate this by following this advice: Use only...Avoid the sun".

In texts with headings such as: "Decide whether you are ready for treatment", the patient is involved in the assessment and decision-making process about their treatment, which corresponds to some of the values in the person-centred approach. The patient has agency and is assigned a specific scope of action, which occurs when the patient is asked to ask themselves 5 questions on the day before the next treatment, e.g.: "Are you unsure whether you are ready for treatment tomorrow?". The patient is involved and is positioned as a competent actor, who has co-determination and can participate in assessment and decision-making, but this does not seem to be a person-centred approach, as it is on the professionals' terms, and not based on the individual person's needs and preferences. Perhaps the patient, because of their medical or mental state, is not able to assess the situation and make all of these decisions.

### *Discourses*

#### **Cancer patient pathways**

At the basis of the linguistic analysis, the positioning of actors, their scope of action and the dominating vocabulary of the texts, more discourses are revealed. The texts of type A draw upon biomedical discourse, where the use of medical terms dominates, e.g.: "Skeletal scintigraphy". In addition to the biomedical discourse, there is also an administrative discourse, which informs about existing rules for cancer patient pathways, determined by state authorities. As only a smaller part of each text has to do with a specific type of cancer, the administrative discourse of the texts is dominant, which is substantiated by the lack of involvement and person-centredness regarding the patient.

The language style used in the purely information leaflets of type B is easy to understand, and the use of medical terms is reduced to a few, in parentheses after the layman's term e.g.: "X-ray (mammogram)". Compared to the administrative and biomedical discourses that dominate type A, the texts of type B are to a greater degree characterised by a care discourse, shown partly in the recipient-oriented use of language, but also through constructions that express person-centredness seen as consideration for the needs of the recipient: "Before treatment ends, you will have a conversation with the staff about your needs, and you will receive a personal follow-up plan". The patient is offered a degree of agency as an active interlocutor.

### Information leaflets on medical treatment and monitoring of patients

In the informative material, a biomedical discourse is generally seen, with the dominant use of medical terms: "...is an antibody that attaches itself to the surface of the body's immune cells (T cells)". In some of the texts, there is a lay discourse with an explanatory text, which imparts knowledge of the body and the pathological conditions, followed by directions for the recipient, e.g.:

You have two lungs in your chest... Cancer in the lungs or cancer from other types of cancer that spreads to the lungs (metastasis) can reduce the passage of air in the respiratory system. This means that you must ... (Onkologisk Afdeling, Aalborg Universitetshospital, 2020).

After this, a prevention discourse appears in the texts, for example in advice to the patient about breathing exercises and relaxation techniques, illustrated by sketches and photos. The prevention discourse is dominant as well in descriptions of how the patient can alleviate different kinds of possible discomfort from cancer treatment (see above), and person-centredness appears here as the opportunity for self-determination and a kind of empowerment line of thinking.

The medical discourse appears to a lesser degree in the action-oriented texts. When it is present, medical knowledge is most often imparted in layman's terms or the medical terms are explained in parentheses: "You will receive a PVC (a small plastic tube inserted in a vein), and through it we can inject...". The action-oriented information leaflets are mostly characterised by a prevention discourse, such as: "You can prevent..." and a rehabilitation discourse: "Routines in everyday life can distract your thoughts from your tiredness. Even a short walk can give you new energy [...]". There are a few tendencies in the texts that point to a care discourse e.g.: "In order for you to experience safety and continuity, you will be assigned a doctor who is responsible for you". Here, person-centredness consists of help in achieving a sense of safety.

### **Dimension 2: Are findings from the present study compatible with results from earlier studies?**

Compared to earlier studies from 2015 and 2018, the patient is assigned greater scope of action in the present information leaflets for patients, even though the scope of action for patients is still limited and primarily reserved for professional staff. The patient appears in the steering documents (Lassen et al., 2015; Lassen et al., 2018), and most often in the data materials from this study as well, as a recipient of and an object of the healthcare staff's

actions. In the steering documents, the patient's scope of action consists of the possibility of free choice of treatment location based on informed knowledge, which has its origin in the New Public Management ideology, where the patient is deemed capable of making rational choices and has the necessary resources for doing so. As clarified in the analyses in this article, the patient is assigned a minimal scope of action in the data as well and is referred to discursively in the same way as in the steering documents. The discursive constructions revealed in the steering documents are thus to a great degree applied to the present data material of this study too. In the texts in 'Cancer patient pathways' from 2018, in the texts from 2010 (Region Nordjylland, 2020) and in the action-oriented information leaflets (Onkologisk Afdeling, Aalborg Universitetshospital, 2020), there are traces of the person-centred approach. Thus, a movement towards a greater degree of person-centredness may be glimpsed, as the conceptual framework for Fundamentals of Care and a person-centred approach is implemented in healthcare education and management. However, as mentioned, there are demands on the patient's personal resources in the present material regarding co-determination, self-determination and assessment, as well as participation in decision-making about treatment, which is discussed by Beauchamp & Childress (2001) and Bredenoord (2018). This line of thinking may be perceived as a consequence of the empowerment ideology that emerged with the growth of New Public Management as a management tool in the healthcare sector (Jensen 2011), and which competed with the traditional welfare ideology.

## Discussion

When the patient is able to take responsibility for monitoring their own symptoms and assessing them, there is an expectation from the healthcare professionals that the patient has the mental and physical resources to assess and make relevant choices about their illness and treatment, that is, an expectation that the patient is capable of mobilising the energy they need to do so. The patient must then be an active participant in the treatment, so that they can help ensure the right treatment. The patient's role as empowered actor is not necessarily consistent with the patient's perception of what they need, and a cancer patient will most likely not have the same ability as a healthy person to act adequately and make sufficient decisions (Beauchamp & Childress, 2001). The basic principles of person-centredness are positive, but in the way that they are expressed discursively in the texts, they do not seem realisable for all patients, and thus they can lead to inequality.

The texts about cancer patient pathways differ regarding patient involvement and person-centredness. This may be due to the fact that cancer patient pathways have been developed over a period of years, where the most recent texts, e.g., the patient pathway for breast cancer from 2018 to a greater degree, take into account the political intentions of patient involvement and patients' responsibility for their own health than pathways developed earlier, such as the bladder and kidney cancer pathway from 2010. Furthermore, the difference in senders: Danish Regions, the Danish Health Authority, the Ministry for Health and Prevention, the Danish College of General Practitioners and Sundhed.dk for some texts, and only the Danish Health Authority for others, could possibly play a role, as the Danish Health Authority as a single sender could implement political intentions without negotiating with other authorities.

In the relatively few texts where the person-centred approach to the patient is represented, this occurs through values such as co-determination, self-determination, respect, involvement, and in one instance through consideration of the needs of the recipient. These values are part of the values common to the theoretical approaches to person-centredness, but the patient's option of making decisions is organised on the professional staff's terms – not according to the patient's preferences, which is the aim of WHO (2016). Nor is the individual care plan developed in cooperation between the patient, family and professional staff, as specified by the Geriatrics Society and Fundamentals of Care (Brummel-Smith et al., 2016). Instead, the patient's knowledge, and their physical and mental resources are expected to serve as the basis for their independent decision-making and assessment, which is the case in most of the data.

Studies of healthcare legislation from 2007 and specifically of the 4 national quality development programmes from 1993 to 2018 (Lassen et al., 2015; Lassen et al., 2018) show that the concept of quality is embedded in a value system with a future vision of a hospital sector that is managed to a greater degree according to the value of interventions seen from the patients' perspectives. This value-based approach makes it necessary for initiatives in the healthcare system to be organised around the different patient populations' needs, in other words, a person-centred approach in collaboration with the individual patient. At the same time, the studies reveal a field of tension, as there is focus on value for the healthcare system too. The New Public Management ideology has been dominant, with a view of the patient as capable of making choices in the healthcare system.

Related to the neo-liberal discourse and the ideology of New Public Management, Rose (2007) characterises the citizen as a 'biological citizen' being assigned with the responsibility of taking care of their own health and illness. This is a tendency which results in the individualization of responsibility. Mol (2008) states that the patient's right to make choices for their own treatment is the dominating rationale in the healthcare system which she calls 'the logic of choice'.

The present study's analysis of regional online information leaflets has confirmed this field of tension, which can have consequences concerning inequality. From a person-centred approach, each person is unique, which means that individuals may have different needs, such as the need for support in assessing their own situation, making choices and decisions, and participating in their own care and treatment. This increases the probability that individuals possessing many personal resources, who are already able to navigate in the healthcare system's services, including seeking information and making demands, are the ones who will have the best access to and outcomes from the services of the healthcare system (Pedersen et al., 2015). There was no consistent value-based approach in the material, or a description following up on a possible implementation of person-centredness in practice. This is not surprising, considering the American Geriatrics Society Expert Panel on Person-Centered Care (Brummel-Smith et al., 2016) and McCormack et.al. (2015)'s conclusions about lack of consensus, uniform definitions and best practice in the person-centred approach in health services. As a starting point for any goal-oriented initiative, it is necessary to have a shared understanding of basic values and how these may be anchored in practice.

Based on research on person-centredness in different countries, including Norway, England, Australia and USA, McCormack et al. (2015) conclude that if person-centred care is to be

practised, a change in the prevailing discourse is necessary, that moves from a discourse of person-centred care towards a discourse of person-centred culture. They argue that person-centred care can only take place if there is a person-centred culture in the workplace that makes it possible for professional staff to experience a person-centred approach and enables them to work in a person-centred way. From this perspective, a person-centred culture should be a mindset among the professional staff and in the organisation as a whole, where the patient's resources, preferences and needs are considered. This means that the healthcare professionals must be able to familiarise themselves with the individual patient's situation, make themselves available to the patient and be willing to enter into dialogue with the patient about how they are managing their illness.

Furthermore, this demands that professionals are willing to implement shared decision-making in practice (Coulter & Collins 2011). For Sepucha et al. (2004, 2008), shared decision-making is paramount for ensuring that patients get the care they need and want, and for real person-centred care. A person-centred culture must also be present in the way the professional staff and management communicate and cooperate, i.e., in the workplace environment, work routines, and in the way work is organised and done (Pedersen et al., 2015).

## Conclusions

Regarding our research questions on the discursive constructions of agency and patient roles, analysis reveals that patients are construed as receivers of services having very limited agency. The patient is only delegated a minimal scope of action in a few situations such as invitation to contact, choices regarding alleviation of discomfort, and a few times in connection with assessment and decision processes about treatment: a recipient-offered treatment determined by the healthcare system. As a layperson and object, the patient is given an identity as a medical case, not as an involved and actively participating person. There are only minor signs of a person-centred approach as seen in the values expressed by WHO (2016), Kitson (2013a, 2013b) and Fundamentals of Care (2019).

The analysis of the discourses reveals that the biomedical and the administrative discourses are dominant. There are a few tendencies towards a care discourse, and it is seen partly in recipient-oriented use of language, but also through constructions that express person-centredness seen as consideration for the needs of the patient and in achieving a sense of safety. A prevention discourse appears as well in descriptions of how the patient can alleviate different kinds of discomfort from cancer treatment, and person-centredness appears here as the opportunity for self-determination and a kind of empowerment thinking.

The present study thus reveals that the patient's scope of action is most often limited, as it was demonstrated in national laws and steering documents from earlier studies (Lassen et al., 2015; Lassen et al., 2018).

## References

- Anthony, L. (2020). AntConc (3.4.0). [Software program]. Faculty of Science and Engineering, Waseda University, Tokyo, Japan. <http://www.laurenceanthony.net/software/antconc/>
- Arribas-Ayllon, M. & Walkerdine, V. (2008). *Foucauldian discourse analysis*. In W. Stainton-Rogers & Willig (Eds.). *The Sage handbook of qualitative research in psychology*, 91-108. Sage.
- Aasen, E.M., Crawford, P. & Dahl, B.M. (2020). Discursive construction of the patient in online clinical cancer pathways information. *Journal of Advanced Nursing*, 76(11), 3113-3122. <https://doi.org/10.1111/jan.14513>
- Baker, P., Gabrielatos, C., Khosravini, M., Krzyzanowski, M., Mcenery, T., Wodak, R. (2008). A useful methodological synergy? Combining critical discourse analysis and corpus linguistics to examine discourses of refugees and asylum seekers in the UK press. *Discourse & Society*, 19(3), 273-306. <https://doi.org/10.1177/0957926508088962>
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. Oxford University Press.
- Bredenoord, A. L. (2018). *The principles of biomedical ethics revisited*. In *Islamic Perspectives on the Principles of Biomedical Ethics: Muslim Religious Scholars and Biomedical Scientists in Face-to-Face Dialogue with Western Bioethicists*. World Scientific Publishing.
- Brummel-Smith, K., Butler, D., Frieder, M., Gibbs, N (2016). American Geriatrics Society Expert Panel on Person-Centered Care: Person-Centered Care: A definition and essential elements. *Journal of the American Geriatrics Society*, 64(1), 15-18. <https://doi.org/10.1111/jgs.13866>
- Coulter, A., & Collins, A. (2011). Making shared decision-making a reality. No decision about me, without me. *King's Fund*, 621.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative and mixed methods approaches*. Sage Publications. 3th edition.
- Fage-Butler, A. (2013). Improving patient information leaflets: Developing and applying an evaluative model of patient-centredness for text. *Communication & Medicine*, 10(2), 105-115. <https://doi.org/10.1558/cam.v10i2.105>
- Fairclough, N. (1995). *Critical discourse analysis: The critical study of language*. Longman.
- Fairclough, N. (2003). *Analysing discourse*. Routledge.
- Folketinget (2020). Folketingets arbejde. [The work of the Parliament]. <https://www.ft.dk/da/folkestyret/folketinget/folketingets-arbejde>
- Forskningsenhed for Klinisk Sygepleje Aalborg Universitetshospital, Klinisk Institut Aalborg Universitet, Sygeplejerskeuddannelsen University College Nordjylland, Psykiatrien Region Nordjylland, Hjemmesygeplejen Aalborg Kommune og Regionshospital Nordjylland (2019). *Forskningsstrategi. Fundamentals of Care. En tværinstitutionel strategi for forskning i Klinisk sygepleje i Region Nordjylland*. [Research Strategy. Fundamentals of Care. A Cross-institutional Strategy for Research in Clinical Nursing in North Denmark Region]. Aalborg, Denmark: Aalborg Universitetshospital, Forskningsenhed for Klinisk Sygepleje.
- Indenrigs- og Sundhedsministeriet (2005). *Kommunalreformen – Kort fortalt*. [The Municipal Reform – In Brief] Indenrigs- og Sundhedsministeriet.
- Jensen, C. (2011). *Velfærdsstaten. En introduktion*. [The Welfare State. An Introduction]. Hans Reitzels Forlag.
- Kitson, A., Marshall, A., Bassett, K. & Zeitz, K. (2013a). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, 69(1), 4–15. <https://doi.org/10.1111/j.1365-2648.2012.06064.x>
- Kitson, A., Robertson-Malt, S. & Conroy, T. (2013b). Identifying the Fundamentals of Care within Cochrane Systematic reviews: The role of the Cochrane Nursing Care Field Fundamentals of care Node'. *International Journal of Nursing Practice*, 109-115. <https://doi.org/10.1111/ijn.12059>

- Lassen, I., Ottesen, A. M., & Strunck, J. (2015). Identitetskonstruktioner af patienter. *Academic Quarter | Akademisk Kvarter*, (12), 136-153. <https://doi.org/10.5278/ojs.academicquarter.v0i12.2732>
- Lassen, I., Ottesen, A. M. & Strunck, J. (2018). Health care policy at a crossroads? A discursive study of patient agency in national health quality strategies between 1993 and 2015. *Nursing Inquiry*, e12252. <https://doi.org/10.1111/nin.12252>
- McCormack, B., Borg, M., Cardiff, S., Dewing, J., Jacobs, G., Janes, N. Wilson, V. (2015). Person-centredness – the ‘state’ of the art. *International Practice Development* 5(5), Special Issue on Person-centredness. <https://doi.org/10.19043/ipdj.5SP.003>
- Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge.
- Onkologisk Afdeling, Aalborg Universitetshospital (2020). Kræftbehandling (onkologi). [Cancer Treatment (Oncology)]. [https://aalborguh.rn.dk/undersogelse-og-behandling/kræftbehandling-\(onkologi\)](https://aalborguh.rn.dk/undersogelse-og-behandling/kræftbehandling-(onkologi))
- Olesen, F. (2010). Den forstærkede patient. [The reinforced patient]. Thorgaard, K., Morten Nissen & Juul Jensen, Uffe (red.). *Viden, virkning og virke – forslag til forståelser i sundhedspraksis*. Roskilde Universitetsforlag.
- Pedersen, L. H., Wandel, A., Freil, M. & Jönson, A. B. R. (2015). Patientinddragelse er endnu ikke fuldt implementeret i sundhedsvæsenet. [Patient Involvement is not yet fully implemented in the Healthcare System]. *Ugeskrift for Læger*, 177(18), 2-5.
- Region Nordjylland (2020). Pjecer om Pakkeforløb for kræft. [Leaflets about Cancer Patient Pathways].
- Rose, N. (2007). *The politics of life itself: Biomedicine, power, and subjectivity in the twentyfirst century*. Princeton University Press.
- Sepucha, K. R., Fowler Jr, F. J., & Mulley Jr, A. G. (2004). Policy Support For Patient-Centered Care: The Need For Measurable Improvements In Decision Quality: Documenting gaps in patients' knowledge could stimulate rapid change, moving decisions and care closer to a patient-centered ideal. *Health Affairs*, 23(2), VAR-54. <https://doi.org/10.1377/hlthaff.var.54>
- Sepucha, K. R., Levin, C. A., Uzogara, E. E., Barry, M. J., O'Connor, A. M., & Mulley, A. G. (2008). Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. *Patient Education and Counseling*, 73(3), 504-510. <https://doi.org/10.1016/j.pec.2008.07.009>
- Sundhedsstyrelsen (2019). Demenshåndbog om personcentreret omsorg i praksis. [Dementia Handbook on Person-centred Care in Practice]. Sundhedsstyrelsen.
- Sundhedsstyrelsen (2020). Om os. [Danish Health Authority. About us]. <https://www.sst.dk/da/Om-os>.
- Sundheds- og Ældreministeriet (2015). Bekendtgørelse om behandling af patienter med livstruende kræftsygdomme. [Act on Treatment of Patients with Life-threatening Cancer Diseases]. <https://www.retsinformation.dk/eli/lta/2015/584>.
- The World Health Organisation (2016). Framework on integrated, people-centred health services. [https://apps.who.int/gb/ebwha/pdf\\_files/WHA69/A69\\_39-en.pdf?ua=1&ua=1](https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1).
- Travelbee, J. (1966). *Interpersonal aspects of nursing*. FA Davis.

