

# Cancer rehabilitation and palliative care for socially vulnerable patients in Denmark: an exploration of practices and conceptualisations

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## Abstract

**Background:** Despite a tax-funded, needs-based organisation of the Danish health system, social inequality in cancer rehabilitation and palliative care (PC) has been noted repeatedly. Little is known about how best to improve access and participation in cancer rehabilitation and PC for socio-economically disadvantaged and socially vulnerable patients.

**Aim:** To gather, synthesise and describe practice-orientated development studies presented in Danish-language publications and examine the underpinning conceptualisations of social inequality and vulnerability; explore related views of stakeholders working in the field.

**Methods:** The study comprised a narrative review of Danish-language literature on practice-orientated development studies which address social inequality and vulnerability in cancer rehabilitation and PC and an online stakeholder consultation workshop with Danish professionals and academics working in the field.

**Results:** Two themes characterise the included publications ( $n=8$ ): types of interventions; conceptualisations of social inequality and vulnerability; three themes were identified in the workshop data: focus and type of interventions; organisation of cancer care; and vulnerability of the healthcare system. The publications and the workshop participants ( $n=12$ ) favoured approaches which provide additional individualised resources throughout the cancer trajectory for this patient group. The terms social inequality and social vulnerability are largely used interchangeably, and associated with low income and no or little education yet qualified with multiple descriptors, which reflect the diverse socio-economic situations professionals encounter in cancer patients and their psychosocial needs.

**Conclusion:** Addressing social inequality and vulnerability in cancer rehabilitation and PC in Denmark entails practical and conceptual challenges. Of importance is individualised support and the integration of rehabilitation and PC into standardised care pathways. To conceive of social vulnerability as a layered, dynamic, relational and contextual concept reflects current practice in identifying the diversity of cancer patients who may benefit from additional support in accessing and participating in rehabilitation and PC.

**Keywords:** cancer care pathway, ethics, palliative supportive care, rehabilitation, social conditions, socio-economic factors, stakeholder perspective

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## Background

Cancer rehabilitation and palliative care are complex health and social care services, consisting of

biomedical and psychosocial interventions provided by interdisciplinary teams of professionals.<sup>1</sup> Rehabilitation and palliative care are often

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required in order to reduce side and late effects of cancer treatment, to maintain and improve functioning and to provide individuals with the support and relief needed in order to enhance their quality of life.<sup>1-3</sup> Despite a tax-funded and needs-based organisation of the Danish health system, and hence largely free access to healthcare for all, social inequality in cancer care has been noted repeatedly in Denmark,<sup>4-10</sup> including in cancer rehabilitation and palliative care.<sup>11-15</sup>

In Denmark, cancer care is governed by a standardised 'cancer package', which includes patients' referral by their general practitioner to hospital for diagnosis, treatment in in-patient and out-patient hospital settings and oncologist's assessment of patient needs and possible referral to community-based rehabilitation and palliative care.<sup>16</sup> Despite this standardised referral pathway embedded in the cancer package, referral to community-based rehabilitation and palliative care is not consistently provided by all hospitals or for all cancer diagnoses.<sup>17</sup> This omission, together with lower access to services and survival-related benefits of rehabilitation and palliative care, disproportionately affects cancer patients who are socio-economically disadvantaged.<sup>10</sup> Low socio-economic position, defined as low educational level, low income and living alone,<sup>18</sup> is shown to impact negatively on access to cancer rehabilitation and palliative care through lower referral rates, lower participation rates, and lack of coordinated and coherent care.<sup>10,11,19,20</sup>

For instance, higher educational level is associated with a higher probability of referral to cancer rehabilitation.<sup>11</sup> Holm *et al.*<sup>19</sup> note that women, and to a lesser extent men, with short education and low income participated less often in cancer rehabilitation activities and had more unmet needs, which leads the authors to conclude that despite equal access to care, socio-economic status has a significant impact on cancer survivors' rehabilitation. Furthermore, cohabiting individuals are favoured in admittance to specialist palliative care, even though it is unlikely that patients living alone have lower needs compared with cohabiting patients.<sup>21</sup> A population-based, cross-sectional register study shows a higher probability of contact with a specialist palliative care team among immigrants and descendants of immigrants than among people of Danish origin and among married compared with unmarried patients; however, no association with economic factors was found.<sup>14</sup> So far, the reasons for the

persistence of these inequalities remain poorly understood.<sup>10</sup>

A number of practice development studies were conducted in Denmark from 2013 onwards in order to improve access, participation, retention and outcome in rehabilitation and palliative care for socio-economically disadvantaged cancer patients or those perceived by professionals to be socially vulnerable for a variety of reasons. These studies tend to be published as local reports and non-peer-reviewed local publications.<sup>22-30</sup> This body of practice-orientated literature provides a wealth of knowledge and experience about different ways of addressing and conceptualising social inequality and vulnerability in cancer care in the context of a social welfare system with free access to care which is also of relevance to an international audience. In addition, a recent scoping review of literature reporting on rehabilitation and palliative care for socio-economically disadvantaged people with advanced cancer has shown that little is known internationally about how to best provide rehabilitation and palliative care for this particular group.<sup>31</sup>

To contribute internationally to debates and developments of how to address and minimise social inequality and social vulnerability in cancer rehabilitation and palliative care, an in-depth exploration of the approaches adopted by this practice-orientated literature is relevant. The aim of this article is therefore to gather, synthesise and describe these practice-orientated studies; examine the underpinning conceptualisations of social inequality and social vulnerability; and explore related views of key stakeholders working in the field.

## Methods

The study comprised two interrelated parts: (1) a narrative review<sup>32</sup> of Danish-language literature that describes practice-orientated development studies concerning cancer rehabilitation and palliative care aimed at addressing and minimising social inequality and social vulnerability (thereafter practice-orientated literature); and (2) a stakeholder consultation through an online workshop with selected Danish health and social care professionals and academics working in the field.<sup>33</sup>

The study was embedded in a larger study entitled Community-based rehabilitation and palliative care for socially vulnerable people with

**Box 1.** Organisations' websites searched.

- Competence Centre for Patient Experiences (Capital Region) – Hospital-based practice development centre, Copenhagen
- Copenhagen Centre for Cancer and Health – Community-based rehabilitation centre, Copenhagen
- Danish Cancer Society – National non-governmental patient organisation
- Danish Health Authority – Part of Ministry of Health
- National Institute of Public Health, University of Southern Denmark – National academic institute
- REHPA – Danish Knowledge Centre for Rehabilitation and Palliative Care – National centre for research, documentation and development of rehabilitation and palliative care

advanced cancer, which comprised several additional substudies, such as registry-linkage studies of trajectories for patients with advanced cancer; a scoping review of existing research of rehabilitation and palliative care for patients with advanced cancer who are socio-economically disadvantaged;<sup>31</sup> focus group interviews with socio-economically disadvantaged and socially vulnerable people with advanced cancer concerning their rehabilitation and palliative care needs and wishes; for further details see <https://www.compas.dk/5-kraeftpatienten-i-det-naere-sundh>. The larger study, in turn, is situated within COMPAS – the Danish Research Center for Equality in Cancer (<https://www.compas.dk/>).

*Review of practice-orientated literature*

The literature review had two interrelated aims: to synthesise and describe the Danish-language practice-orientated literature and to explore the conceptualisations of social inequality and social vulnerability underpinning this body of literature.

The literature included in this narrative review was identified by the first author through searching websites of relevant organisations (see Box 1), contacting experts in the field working in Denmark and hand-searching publications.

In addition, the first author approached selected individuals in the organisations listed in Box 1 and the Danish Research Center for Equality in Cancer (COMPAS); all identified literature was hand-searched for possible additional publications.

Publications were included if they met the following criteria:

- Reporting on practice development studies from the perspectives of health and social

care professions in cancer rehabilitation and palliative care aimed at addressing social inequality and vulnerability (or related terminology);

- Non peer-reviewed;
- Published in Danish;
- Published between 2010 and 2020 (the time period between two major national reports on social inequality in health and illness).<sup>34,35</sup>

*Stakeholder consultation workshop*

The stakeholder consultation workshop (thereafter ‘workshop’) had two aims: to elicit participants’ experiences of and opinions on the main challenges encountered in practice when seeking to reduce inequality in cancer rehabilitation and palliative care; to gather participants’ suggestions on how to improve access, participation and retention in cancer rehabilitation and palliative care for people who experience social inequality or social vulnerability.

The workshop was held online (*via* Zoom) in February 2021 and lasted 4h, including short breaks. Possible participants were selected from among the authors of the included publications; specialists and organisations in the field (for list of organisations, see Box 1) and members of REHPA – The Danish Knowledge Centre for Rehabilitation and Palliative Care and of COMPAS were approached for additional suggestions. The main selection criterion was clinical practice or research expertise in the field of social inequality/vulnerability in health care, particularly cancer rehabilitation and palliative care.

Given the aims of the workshop, a discussion format was adopted. This was facilitated through a presentation (by the first author) of the preliminary findings of the narrative review, followed by a focused discussion of two main questions:

- In your opinion, what are the most prominent challenges which need to be addressed in order to address and reduce social inequality and social vulnerability in cancer rehabilitation and palliative care?
- Do you have specific recommendations regarding how best to reach this group of cancer patients and how rehabilitation and palliative care aimed at this patient group could be organised?

In this way, the participants reflected key professional actors in the field of social inequality/vulnerability in cancer rehabilitation and palliative care and the workshop methodology adopted a user-involving approach to exploring the topic and eliciting stakeholder opinions.<sup>33</sup> Notes were taken throughout and the discussion was audio-recorded with permission.

The workshop was organised by three researchers with different disciplinary affiliations [medical anthropology (N.N.), occupational science (K.I.C.) and public health (H.K.R.)] and with diverse expertise in cancer rehabilitation and palliative care.

#### *Data extraction and analysis*

The first author extracted data from the literature in Microsoft Excel, including bibliographic details; aims/purpose of the studies; methodology/methods; key findings relating to review's aim and research questions; and authors' main conclusions.

All data were analysed using thematic content analysis, which is a useful approach for answering questions about salient issues, such as arising from the included literature, or identifying typical responses for a group of participants, such as workshop participants.<sup>36</sup> To establish basic descriptive themes, the first author read the included publications repeatedly, analysed notes taken during the workshop and listened to the audio-recording of the workshop discussion, throughout remaining closely grounded in the data.<sup>37,38</sup> Themes emerging from the analysis of the literature and the workshop data were discussed and refined by the author team.

#### *Ethics*

The study adhered to the standards for good scientific practice set out in the Danish Code of

Conduct for Research Integrity (<https://ufm.dk/en/publications/2014/the-danish-code-of-conduct-for-research-integrity>), which emphasises honesty, transparency and accountability as the three guiding principles of good scientific practice, and the Danish law on research integrity (<https://ufm.dk/en/research-and-innovation/councils-and-commissions/The-Danish-Committee-on-Research-Misconduct>).

Together with the workshop invitation, participants received written information about the purpose of the workshop and the planned use of data. All participants gave prior written and verbal consent to recording the discussion and the use of resulting material for publication. Data were anonymised, treated confidentially and stored on a secure site available through REHPA – The Danish Knowledge Centre for Rehabilitation and Palliative Care.

## **Results**

### *Review of practice-orientated literature*

*The publications and associated studies: an overview.* Eight publications (seven reports<sup>23–25,27–30</sup> and one non-peer-reviewed article)<sup>22</sup> met the inclusion criteria, out of a total of 35 located publications which broadly addressed topics concerning (cancer) rehabilitation, palliative care and social inequality or social vulnerability in health and illness. The included publications derived from four practice development studies which were conducted between 2013 and 2017 and led by four different organisations; for details, see Table 1 (all translations by the authors).

Our analysis identified two interrelated themes: types of interventions developed and conceptualisations of social inequality and social vulnerability. These themes are examined in the following section.

### *Types of interventions*

Following Flink *et al.*,<sup>26</sup> the interventions underpinning the four studies can be grouped into three categories: supporting the dialogue between cancer patients and health professionals in consultations; additional resources offered to cancer patients deemed socially vulnerable; and the organisation of rehabilitation and palliative care. Interventions supporting the dialogue between cancer patients and professionals can be

**Table 1.** Included publications, studies and organisations.

Included publications	Study	Organisation
Hassani <i>et al.</i> <sup>22</sup> Pedersen <i>et al.</i> <sup>23</sup>	Equality in rehabilitation in the Copenhagen Centre for Cancer and Health	Copenhagen Centre for Cancer and Health
Flink <i>et al.</i> <sup>24</sup> Flink <i>et al.</i> <sup>25</sup>	Involvement of socially vulnerable cancer patients	Competence Centre for Patient Experiences
Jerris <sup>27</sup> Rasmussen <i>et al.</i> <sup>28</sup>	Bridge building for vulnerable families with children. A 360 degree initiative	Crossdisciplinary Knowledge Centre for Patient Support
Nissen <sup>29</sup> Scheuer <i>et al.</i> <sup>30</sup>	Navigator Programme	Danish Cancer Society

subdivided further into interventions aimed at patients and those aimed at professionals. For further details, see Table 2.

Overall, all the interventions aimed to improve access and participation in cancer rehabilitation and palliative care. Three interventions aimed to do so through providing additional resources, offering ‘help to self-help’ in the course of the cancer trajectory (see Table 2); two of these (*Equality in Rehabilitation*; *Bridge Building*) were particularly concerned with psychosocial support.

The intervention in the community-based study ‘*Equality in Rehabilitation*’ employed a nurse with the remit to encourage patients with ‘special and complex rehabilitation needs’, including those with mental health issues, to join or remain in community-based rehabilitation, as well as to support patients to gain access to the practical and financial support they are entitled to from the municipality. The support offered by the specialist nurse included an initial home visit of a socially vulnerable patient followed by regular phone calls with the patient, leading to significantly more telephone contact when compared with other cancer patients; involvement of a social worker if requested by the patient; and consultation with a dietician if wanted by the patient.<sup>22</sup>

The intervention of the study *Bridge Building* was also concerned with psychosocial support, in this instance, families with young children where an adult was diagnosed with cancer. The overarching aim of the intervention was to ‘support vulnerable families with children to get through the disease trajectory as well as possible’,<sup>27</sup> with a focus on the whole family. The remit of the team

of psychologist and social worker, based in a hospital setting, was to build bridges between and across different health and social care sectors responsible for delivering rehabilitation. In this way, the intervention was to address the challenges which can arise due to a combination of health-related and psychosocial problems and ‘build bridges between disease trajectory and everyday life’.<sup>27</sup> At the same time, by drawing on a cross-disciplinary team, the project also built bridges between different health and social care sectors and their professions.

By contrast, through adding the resource of a volunteer navigator, the *Navigator Programme* focused predominantly on supporting the communication in patient-health professionals encounters in hospital settings, whereby ‘communication’ and ‘encounters’ were broadly understood.<sup>29</sup> For instance, navigators aimed to ease patients’ access to and participation and retention in cancer care through supporting the keeping of appointments across different hospital departments and community settings, identifying patients’ needs and wishes prior to appointments, and assisting in consultations with professionals. In addition to such practical support, navigators were also expected to offer emotional support to participating cancer patients. Although the navigators were volunteers, a majority (72%) had professional backgrounds, for example in health and social care professions, social work and education.<sup>30</sup>

By focusing on increasing cancer nurses’ communication skills when meeting (and treating) socially vulnerable patients, the study *Involvement of socially vulnerable cancer patients* is the only project that specifically falls into the category of ‘dialogue support’, as suggested by Flink *et al.*<sup>26</sup> The

**Table 2.** Types of interventions.

Study	Additional resource	Dialogue support		Organisation of intervention
		Patients	Professionals	
Equality in rehabilitation in the Copenhagen Centre for Cancer and Health (short: Equality in Rehabilitation)	Nurse with social work expertise			
Involvement of socially vulnerable cancer patients		Video (about palliative care)	<ul style="list-style-type: none"> <li>• Conversation tool, together with user guide</li> <li>• Personal Plan (form)</li> <li>• Scheduled follow-up</li> <li>• Marking of patient notes with clover leaf</li> </ul>	
Bridge building for vulnerable families with children. A 360 degree initiative (short: Bridge Building)	Psychologist and social worker			Cross-professional Cross-sectorial
Navigator programme	Volunteer navigator			

developed conversation tools and associated guidelines aimed to elicit cancer patients' needs and priorities during an initial consultation. These then were formulated into 'plans' and 'action points' agreed between patient and nurse for later follow-up. Agreed plans aimed to put 'the patient in the centre' and ensure patients' participation in care, for example, through shared decision-making about care options. Additional elements included guidelines for nurses for this personal conversation and the marking of a patient's medical notes with a clover leaf which identified the patient as 'socially vulnerable' to all who have access to a patient's medical notes. A short information video about palliative care constituted a minor project element and addressed the information needs of patients and their relatives.<sup>24,25</sup>

*Conceptualisations of social vulnerability and social inequality*

The included publications are characterised by a diversity of terms and understandings which are seen to mark the interventions' intended group of cancer patients – social inequality, social vulnerability, social position, social marginalisation and social class. The terms are largely used interchangeably, with the term social vulnerability used most frequently and therefore also used

throughout in this article. No consistency can be identified in how the term social vulnerability is understood; indeed, each study uses its own definition and definitions may vary between publications from the same study<sup>29,30</sup> or change throughout the life of a study.<sup>24,25,27,28</sup>

Social vulnerability, as presented in each publication, consists of an array of, for example, 'indicators', 'vulnerability factors', 'background factors', 'signs', 'characteristics' and 'perspectives' which are combined in idiosyncratic ways. Two 'indicators' or 'vulnerability factors' stand out across the studies: no or little education, and low income. These tend to be further qualified through additional descriptors of social vulnerability, such as financial circumstances, communicative resources and social contexts. Further descriptors are summarised in Box 2, roughly in descending order of ascribed importance and frequency mentioned. The aimed-for group of cancer patients is referred to as 'target group' by the publications' authors.

The term social inequality is only used in the anthropological study reported by Pedersen *et al.*<sup>23</sup> Following Moustsen *et al.*,<sup>11</sup> the authors define social inequality on the basis of the indicators 'no or little education' and 'low income'. The report's authors, however, also mention that they encountered a 'degree of uncertainty' and at times

**Box 2.** Descriptors of indicators or vulnerability factors.

## 1. Financial circumstances

Low income is further associated with having loose or no connection to the job market<sup>22,27</sup> or being 'outside the employment market', due to receiving unemployment-, sickness- and other social benefits or early retirement pension.<sup>30</sup>

## 2. Communicative resources

Low educational status tends to be qualified and signalled by a lack of communicative resources, including difficulties to read and comprehend information<sup>24,29</sup> and limited Danish language proficiency.<sup>22</sup>

## 3. Social contexts

Limited social networks, including being single or living alone, and loneliness are frequently thought to shape social vulnerability<sup>22,24,27,29,30</sup> as may unstable housing situations and 'burdensome family circumstances'.<sup>22,27</sup>

## 4. Health-related issues

A number of different health-related factors are also perceived to contribute to or constitute social vulnerability. These include multimorbidity and disability,<sup>22,30</sup> mental health problems<sup>22,27</sup> and current or previous substance abuse.<sup>22,27</sup>

## 5. Personal resources

Lack of trust in health and social care systems is perceived to shape attitudes towards healthcare provision and health professionals.<sup>24</sup>

even 'discomfort' in the participating health and social care professionals, which related to the categorisation of a distinct group of people. This uncertainty manifested with a need to emphasise the many differences encountered in people in the 'target group'. Accordingly, the interviewees used qualifying descriptions and characteristics, in addition to educational level and income, when referring to this group of patients. Qualifiers included weak social network, unemployment or reference to the target group's health behaviours. The interviews thus revealed the contours of a grouping of people who are perceived to be socially vulnerable; that is, a group of patients who both hospital and community-based professionals recognise as such in their work.<sup>23</sup>

An additional aspect of how social vulnerability is conceptualised concerns the descriptor 'socially marginalised'. The term is frequently used in the publications (with the exception of the works by Nissen<sup>29</sup> and Scheuer *et al.*<sup>30</sup>) by both the publications' authors and the interviewed health and social care professionals, but remains undefined. However, indications point to a perception that socially marginalised individuals constitute a particular group. This group, overall, appears to be seen as especially vulnerable and is thus positioned as a subgroup within the group of patients who are described as socially vulnerable.<sup>22</sup>

Flink *et al.*<sup>24</sup> note that vulnerability is not necessarily connected to what they refer to as 'objective vulnerability factors' and thus tied to individuals. Rather, vulnerability can also arise in the meeting between individuals and the (healthcare) system. This shift in perspective from an individual patient to the healthcare system and the contact between patient and system also shifts, the authors argue, responsibilities away from a patient and focuses on the situation in which patient and system meet and interact.<sup>24</sup>

Because of the diverse understandings of social vulnerability in the included body of literature, the issue of identifying the target group to be included in any intervention was addressed in most publications. Some studies, such as *Involvement of socially vulnerable cancer patients*, screened patients with an 'identification form' completed by a nurse during an initial consultation. The form reflected the study's understanding of social vulnerability and included key headings and associated questions: networks and social support; understanding of disease and its treatment and collaboration with professionals; personal factors; and treatment trajectory; for further details, see Box 3.

By contrast, other studies (*Bridge Building* and *Navigator Programme*) relied on professionals' subjective evaluation of patients' social

**Box 3.** Identifying target group: key headings.

- Network and social support, for example
  - Complicated family relationships
  - Sick spouse/partner
- Understanding of disease and collaboration with professionals, for example
  - Need for additional support in communication with health professionals
  - Cognitive impairment
- Personal factors, for example
  - Social security benefits, disability pension
  - Complicated housing situation
  - Multimorbidity
  - Language/cultural barriers
- Treatment trajectory
  - No-shows to appointments

vulnerability and the professionals' ability to identify vulnerable cancer patients. These differences point to a tension between 'being systematic' and valuing professionals' intentions and expertise to meet the needs of all patients.<sup>25</sup>

### Workshop

Of the 17 individuals invited by email, 12 took part; two invitees declined due to time pressures, one was on maternity leave, one no longer worked in the field of (cancer) rehabilitation and palliative care, and one did not respond. The 12 workshop participants pertained to different stakeholder groups: health and social care professionals ( $n=9$ ), a representative of the Danish Cancer Society ( $n=1$ ) and academics ( $n=2$ ). Six participants were co-authors of included publications, 'representing' three of the four studies.

The analysis of the workshop data identified three themes: intervention focus and type of interventions; organisation of cancer care; and vulnerability of the healthcare system. These themes are presented in the following sections.

#### *Focus and types of interventions*

Workshop participants agreed on the need to improve current approaches and interventions rather than invent new ones, despite the limitations of current provision. Improvements should focus on 'simple solutions', and these should be made 'more usable and effective'. Furthermore, participants stressed that the perspectives of this particular group of cancer patients, the 'target group', should inform next steps and care should be taken to integrate their views when modifying

existing provisions. With these caveats, several observations and suggestions were made.

The participants unanimously stressed the importance of person-centred interventions which take patients' own needs and priorities as a starting point, rather than the needs and priorities identified by health and social care professionals from their professional perspectives. To promote and facilitate access and participation in rehabilitation and palliative care, they considered interventions which 'hold people's hands' to be the most appropriate. They further stressed the importance of 'building-in' both continuity in professionals' interactions with this group of patients and flexibility in terms of, for example, when and how people access services or take part in activities.

No agreement was reached on what some participants referred to as 'parallel' provision. Several participants had experience in cross-disciplinary settings and interventions aimed at socio-economically and socially vulnerable (cancer) patients. Based on these experiences, they put forward the suggestion of gathering a wide range of expertise into one location, either for example a specific hospital department or an independent 'house', to which patients could be referred to or refer themselves. Others pointed out that 'parallel' provision for specific target groups, such as socially vulnerable cancer patients, could increase stereotyping and their marginalisation and offer 'second class' provision outside mainstream services. In addition, parallel provision might de-skill health and social professionals working in mainstream provision, leading to overall poorer encounters and services for all patients.



The discussion clearly pointed to a preference for approaches which provide added individual resources, such as the examples described in the practice-orientated literature above. Other options, some participants indicated, should however not be discarded without further in-depth consideration of possible practical and ethical implications.

#### *The organisation of cancer care*

A possible modification to the current standardised ‘cancer package’ was highlighted as an example of a pragmatic solution to improving access to cancer rehabilitation and palliative care. As noted above, this currently includes general practitioner (GP) referral to hospital for diagnosis, treatment and assessment of patient needs and possible referral to community-based rehabilitation and palliative care. In practice, however, these pathways are characterised by social inequality in access to, participation and retention in rehabilitation and palliative care. In order to improve uptake of rehabilitation after discharge from hospital and during the resulting transition to community-based rehabilitation and palliative care in the municipality, participants suggested that rehabilitation and palliative care in the community should be included in the standard ‘cancer package’. Streamlining and extending the cancer package to municipality-provided services, participants suggested, would likely facilitate access and improve uptake by at least some patients in this group.

#### *The vulnerability of the healthcare system*

Several participants expressed the view that the Danish healthcare system itself is vulnerable. This, they pointed out, manifests in its complexity, lack of flexibility, and lack of transparency of its structure, organisation and organisational rationale. One participant, for example, commented: ‘The health care system has come to its end, it builds on old structures’, and another said: ‘One should not just build on an old house where the foundation is not stable – in this case simpler solutions easily applicable in practice are better’.

Participants agreed that all patients are affected by these structural and organisational issues, though socially vulnerable patients were thought to be particularly negatively affected, as Flink *et al.*<sup>24</sup> also report. The ‘cancer package’ itself was

seen as one example of this complexity, while pragmatic changes to its organisation were thought to improve access to and participation in cancer rehabilitation and palliative care for at least some socially vulnerable patients.

#### **Discussion**

In this study, we set out to gather, synthesise and describe recent Danish practice-orientated development studies of cancer rehabilitation and palliative care which seek to address social inequalities and vulnerabilities, together with underpinning conceptualisations of social inequality and social vulnerability and the perspectives of diverse stakeholders working in this field. To this end, we examined selected practice-orientated literature published in Danish and explored findings from a discussion-based workshop with key stakeholders. Our findings highlight diverse issues which come into play when seeking to improve access, participation and retention in cancer rehabilitation and palliative care for socio-economically disadvantaged and socially vulnerable cancer patients. Foremost are issues around how best to meet the needs of cancer patients who are deemed to be socially vulnerable and understandings of vulnerability, both individually and systemically.

The majority of practice-orientated projects examined in the included literature focus on added professional or volunteer support for individual cancer patients and their families. Workshop participants similarly stressed the need for individual and individualised support and guidance for this group of cancer patients. These issues are also thought internationally to be important aspects.<sup>2,3</sup> It is, however, noteworthy that possible cost implications of service modifications were neither addressed in the included literature nor explicitly discussed during the stakeholder workshop. This may be due to the practice orientation of the development studies, the stakeholders’ focus on patients’ needs, as well as the participants’ shared values of solidarity and equality which are also embedded in the Danish welfare system, including the healthcare system.<sup>39</sup>

Acutely aware of the limitations of effecting possible improvements within the current healthcare system and its structure in order to improve access and participation in rehabilitation and palliative care for socially vulnerable cancer patients,

the workshop participants' unanimous proposal was informed by pragmatism and realism. Rather than propose system-level changes or invent new interventions, they advocated 'tweaking' and thus improving existing provision and interventions, such as expanding routine referral to rehabilitation and palliative care as part of the standardised cancer package.<sup>16</sup> This, they argue, would support a wider range of cancer patients in accessing and participating in cancer rehabilitation and palliative care without a need for categorisation and possible stigmatisation. Such an expansion, however, fails to address the barriers experienced by those cancer patients who do not access services in the first place. Some of these barriers may be related to an additional point stressed by the participants, namely: the importance of grounding provision in patient-identified needs rather than professionals' perceptions thereof. This may yet prove to be a possibly unexpected stumbling block, since cancer patients deemed socially vulnerable by professionals may not always share this professional assessment.<sup>23,27</sup>

Multiple challenges concerning the 'target group' and how this group of socially vulnerable cancer patients might be identified were noted in all the included publications. The challenges reveal tensions between epidemiological and bioethical approaches, such as lower access to cancer rehabilitation and palliative care by socio-economically disadvantaged people and the ethical commitment to treating all patients equally irrespective of socio-economic background. These challenges were also acknowledged during the workshop discussion. In addition, workshop participants perceived a vulnerability of the healthcare system, due to its complexity and lack of organisational and structural transparency, a perspective which offers a striking understanding of vulnerability. These findings raise the issue of how vulnerability can be conceptualised and understood.

From the perspectives of bioethics and public health ethics, the concept of vulnerability refers to the effects of inequalities on a population regarding health and care, whereby the term vulnerable groups describes certain kinds of populations, such as those marked by gender, low education or socio-economic status, deemed worthy of protection.<sup>40,41</sup> The classification of vulnerable groups has been criticised as potentially stigmatising and stereotyping,<sup>41,42</sup> concerns which were also expressed in the practice-orientated literature<sup>23,27</sup>

and by workshop participants. Luna<sup>41,43</sup> further suggests that fixed classifications of vulnerable groups prevent the identification of more nuanced levels of vulnerability, a problem repeatedly mentioned in the literature reviewed here and reflected in the multiple 'qualifiers' professionals draw on to refer to and identify the 'target group'.

To address these concerns, Luna proposes to conceive the concept of vulnerability *via* a notion of layers.<sup>41</sup> According to Luna, vulnerability is not a static category or label but rather a dynamic, relational and contextual concept closely related to the situation under analysis. This, in turn, allows for the accumulation of conditions comparable to layers of situations and their changeability over time.<sup>41,43</sup> In this way, 'vulnerability obeys complexity' which entails variability and changeability of social situations and acknowledges the presence of multiple types of vulnerabilities, such as socio-economic status, physical and emotional health, social support and networks, and housing.<sup>44</sup> Further acknowledged are the difficulties in assessing vulnerabilities and their diverse interpretations depending on regions of the world,<sup>44</sup> and – one may add – the organisational and structural differences in healthcare systems and provisions.

Drawing on this layered approach to vulnerability both reveals and can help to explain the challenges reported in the reviewed practice-oriented literature. The diversity of 'qualifiers' can be said to reflect the various situations professionals encounter in cancer patients, and the diversity of cancer patients' psychosocial needs. Thus, the identification of social vulnerability is based on a 'social diagnosis' which establishes, for example, family situation, social, economic and employment status, and linguistic and cultural backgrounds and skills.<sup>44</sup> Layered and flexible, these markers shape professionals' perceptions of patients' vulnerability which may also change over time and during the course of cancer care. A social diagnosis may be conducted through a check-list (see Box 3) or on the basis of professionals' experience, their endeavours to meet the needs of all patients and the claim to treat all patients equally regardless of social class, education, income or other social differences such as gender, age or disability.<sup>23</sup> Yet, persistent social inequalities in cancer rehabilitation and palliative care in Denmark belie these claims and efforts.

The Danish healthcare system is largely based on a one-size-fits-all approach, such as the

standardised cancer package,<sup>39</sup> a normative approach which is partly built on the cultural construction of homogeneity and based on middle class experiences and norms.<sup>39,45</sup> Bendixsen *et al.*<sup>45</sup> argue that willingness to conform is often the criterion for access to the benefits of the welfare state such as the healthcare system. Indeed, Merrild<sup>39</sup> suggests that social inequality in cancer care in Denmark provides a challenge to the healthcare system and its claims to equality. As a result, discussions of equality of access to existing services may appear more prominent, compared with equity-informed services (for further discussion of these issues, see Sundhedsstyrelsen<sup>34</sup>).

The vulnerability of the Danish healthcare system noted by the workshop participants can be understood in the light of this. The complexity of care provision, the lack of flexibility and organisational and structural transparency, together with the cultural norms and expectations which govern its functioning, limit its accessibility and patients' participation in their care. This not only shapes the meeting between cancer patients deemed socially vulnerable and individual professionals as well as how these patients are met by the health and social care system,<sup>23</sup> but also reveals a profound institutional (and societal) failure to live up to its claims of meeting the health needs of all. The vulnerability of the health (and social care) system, it can be suggested, lies in not achieving its goals, underscoring Merrild's contention that social inequality in cancer care challenges the Danish health and social care system.<sup>39</sup>

### Limitations

Despite a comprehensive literature search of Danish practice-orientated studies in the field, some relevant publications may have been missed. The nature and quality of grey literature tends to be variable, which can be perceived as limiting the trustworthiness of findings derived from the narrative review. Nevertheless, the problems identified both in the literature and in the stakeholder workshop highlight their relevance also to an international audience. The workshop was conducted online, which may have limited the depth of discussion compared with an in-person workshop. The discussion-orientated format of the online workshop circumscribed the number of participants, though key stakeholders joined the workshop; an extended invitation may, however, have allowed additional information to emerge.

### Implications

To improve cancer rehabilitation and palliative care for all patients, more attention needs to be paid to barriers to access of services, and to issues of inequality and inequity in health. Understandings of vulnerability impact access to support, services and resources, as well as potential modifications of provision.

In the present study, we gathered evidence-based knowledge from practice-orientated studies and consulted health and social care professional and academic stakeholders on how to improve access to and participation in existing rehabilitation and palliative care for the target group. In the next step, cancer patients who are deemed to experience socio-economic disadvantage and be socially vulnerable should be consulted on the issues identified in this study in order for their views to inform future research and practice developments.

### Conclusion

Seeking to address social inequality and social vulnerability in cancer rehabilitation and palliative care in Denmark entails practical and conceptual challenges. Many of the problems identified and the suggestions made for improvement in the Danish context are equally applicable to health services worldwide. Of particular importance is individual and individualised support for socially vulnerable cancer patients and the integration of rehabilitation and palliative care into standardised cancer care referral pathways. Existing provision should be improved in order to make it more effective, instead of developing new and parallel services, which may further stigmatise and marginalise particular groups of cancer patients. To conceive of social vulnerability as a layered, dynamic, relational and contextual concept reflects current practice in identifying the diversity of cancer patients who may benefit from additional support in accessing and participating in rehabilitation and palliative care that address their needs. This indicates a need for greater flexibility than the current standardised cancer care allows.

### Ethics approval and consent to participate

The research was conducted in accordance with the Danish Code of Conduct for Research Integrity (<https://ufm.dk/en/publications/2014/the-danish-code-of-conduct-for-research-integrity>), and the Danish law on research integrity (<https://ufm.dk/en/research-and-innovation/councils-and-commissions/The-Danish-Com>

mittee-on-Research-Misconduct). All participants received written information about the purpose of the workshop and the planned use of data, and gave prior written and verbal consent to recording the workshop discussion.

### Consent for publication

All participants consented to the use of workshop data for publication.

### Author contribution(s)

**Nina Nissen:** Conceptualisation; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing.

**Henriette Knold Rossau:** Conceptualisation; Formal analysis; Investigation; Project administration; Writing – review & editing.

**Marc Sampedro Pilegaard:** Formal analysis; Methodology; Writing – review & editing.

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### References

1. Silver JK, Raj VS, Fu JB, *et al.* Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services. *Support Care Cancer off J Multinat Assoc Support Care Cancer* 2015; 23: 3633–3643.
2. World Health Organization. Palliative care, 2020, <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
3. World Health Organization. Rehabilitation, 2021, <https://www.who.int/news-room/fact-sheets/detail/rehabilitation>
4. Eriksen KT, Petersen A, Poulsen AH, *et al.* Social inequality and incidence of and survival from cancers of the kidney and urinary bladder in a population-based study in Denmark, 1994–2003. *Eur J Cancer Oxf Engl* 2008; 44: 2030–2042.
5. Frederiksen BL, Brown P, de N, *et al.* Socioeconomic inequalities in prognostic markers of non-Hodgkin lymphoma: analysis of a national clinical database. *Eur J Cancer Oxf Engl* 2011; 47: 910–917.
6. Ibfelt E, Kjær SK, Johansen C, *et al.* Socioeconomic position and stage of cervical cancer in Danish women diagnosed 2005 to 2009. *Cancer Epidemiol Biomarkers Prev* 2012; 21: 835–842.
7. KÅrsgaard Starr L, Osler M, Steding-Jessen M, *et al.* Socioeconomic position and surgery for early-stage non-small-cell lung cancer: a population-based study in Denmark. *Lung Cancer* 2013; 79: 262–269.
8. Dalton SO, Frederiksen BL, Jacobsen E, *et al.* Socioeconomic position, stage of lung cancer and time between referral and diagnosis in Denmark, 2001–2008. *Br J Cancer* 2011; 105: 1042–1048.
9. Dalton SO, Schüz J, Engholm G, *et al.* Social inequality in incidence of and survival from cancer in a population-based study in Denmark, 1994–2003: summary of findings. *Eur J Cancer Oxf Engl* 2008; 44: 2074–2085.
10. Olsen MH, Kjær TK, Oksbjerg S, *et al.* *Social Ulighed i Kræft i Danmark. Hvidbog* [Social inequality in cancer in Denmark. Whitebook]. København: Kræftens Bekæmpelses Center for Kræftforskning [Danish Cancer Society Research Center], 2019.
11. Moustsen IR, Larsen SB, Vibe-Petersen J, *et al.* Social position and referral to rehabilitation among cancer patients. *Acta Oncol* 2015; 54: 720–726.

12. Oksbjerg Dalton S, Halgren Olsen M, Moustsen IR, *et al.* Socioeconomic position, referral and attendance to rehabilitation after a cancer diagnosis: a population-based study in Copenhagen, Denmark 2010–2015. *Acta Oncol* 2019; 58: 730–736.
13. Adersen M, Thygesen LC, Neergaard MA, *et al.* Admittance to specialized palliative care (SPC) of patients with an assessed need: a study from the Danish palliative care database (DPD). *Acta Oncol* 2017; 56: 1210–1217.
14. Neergaard MA, Jensen AB, Olesen F, *et al.* Access to outreach specialist palliative care teams among cancer patients in Denmark. *J Palliat Med* 2013; 16: 951–957.
15. Hindhede AL, Bonde A, Schipperijn J, *et al.* How do socio-economic factors and distance predict access to prevention and rehabilitation services in a Danish municipality. *Prim Health Care Res Dev* 2016; 17: 578–585.
16. Sundhedsstyrelsen [Danish Health Authority]. *Forløbsprogram for rehabilitering og palliation i forbindelse med kræft* [Course programme for rehabilitation and palliative care in cancer]. København: Sundhedsstyrelsen [Danish Health Authority], 2018.
17. Thuesen J, Rossau HK, Frausing S, *et al.* *Kræftrehabilitering i Danmark. Kortlægning af praksis på hospitaler og i kommuner* [Cancer rehabilitation in Denmark. Mapping practice in hospitals and municipalities]. Nyborg: REHPA, 2017.
18. Galobardes B, Shaw M, Lawlor DA, *et al.* Indicators of socioeconomic position (part 1). *J Epidemiol Community Health* 2006; 60: 7–12.
19. Holm LV, Hansen DG, Larsen PV, *et al.* Social inequality in cancer rehabilitation: a population-based cohort study. *Acta Oncol* 2013; 52: 410–422.
20. la Cour K and Cutchin MP. Developing community based rehabilitation for cancer survivors: organizing for coordination and coherence in practice. *BMC Health Serv Res* 2013; 13: 339.
21. Adersen M, Thygesen LC, Neergaard MA, *et al.* Cohabitation status influenced admittance to specialized palliative care for cancer patients: a nationwide study from the Danish palliative care database. *J Palliat Med* 2019; 22: 164–172.
22. Hassani AR, Rossen S and Andersen CW. Socialfaglig sygeplejerske kan mindske ulighed i sundhed [A nurse with social work expertise can reduce inequality in health]. *Sygeplejersken* 2020; 2: 30–35.
23. Pedersen PV, Ingholt L and Tjørnhøj-Thomson T. *Når man har sagt A, må man også sige B: Om social ulighed i kræftrehabilitering* [Having said A, one must also say B: on social inequality in cancer rehabilitation]. København: Statens Institut for Folkesundhed, Syddansk Universitet, 2015.
24. Flink CE, Kehlet KH and Gut R. *Inddragelse på lige fod. Oplevelser med og ønsker til inddragelse blandt socialt sårbare kræftpatienter* [Involvement on equal terms. Experiences with and wishes for involvement among socially vulnerable cancer patients]. København: Kompetencecenter for Patientoplevelser, 2017.
25. Flink CE, Kehlet KH and Gut R. *Inddragelse af socialt sårbare kræftpatienter. Praksiserfaringer og evaluering af to inddragelsesindsatser* [Involvement of socially vulnerable cancer patients. Practice experiences and evaluation of two involvement initiatives]. København: Kompetencecenter for Patientoplevelser, 2018.
26. Flink CE, Kehlet KH, Rogvi S, *et al.* *Kortlægning af danske initiativer til inddragelse af socialt sårbare patienter* [Mapping of Danish initiatives for the involvement of socially vulnerable patients]. København: Kompetencecenter for Patientoplevelser, 2017.
27. Jerris T. *Brobygning for sårbare børnefamilier – en 360 grader indsats* [Bridge building for vulnerable families with children – a 360 degree initiative]. København: Tværfagligt Videnscenter for Patientstøtte, Oktober 2015.
28. Rasmussen PS, Larsen PT and Hjelmar U. *Kvalitativ interviewundersøgelse af 360-grader indsats til sårbare patienter og deres familier* [Qualitative interview study of the 360-degree initiative for vulnerable patients and their families]. København: KORA – Det Nationale Institut for Kommuners og Regioners Analyse og Forskning, September 2015.
29. Nissen A. *Navigatorprogram for kræftpatienter* [Navigator programme for cancer patients]. København: Kræftens Bekæmpelse, 2015.
30. Scheuer S, Thomsen CF and Rix BA. *Evaluering af Navigatorprojektet – Kræftens Bekæmpelses nationale indsats målrettet socialt sårbare kræftpatienter. Kan frivillige navigatore forbedre socialt sårbare kræftpatienters trivsel, sundhedskompetencer og sociale netværk?* [Evaluation of the Navigator project – The Danish Cancer Society's national initiative targeted at socially vulnerable cancer patients. Can volunteer navigators improve the well-being, health skills and social networks of socially vulnerable cancer patients?]. København: Kræftens Bekæmpelse Patient- & Pårørendestøtte, 2018.

31. Pilegaard MS, Rossau HK, Lejsgaard E, *et al.* Rehabilitation and palliative care for socioeconomically disadvantaged patients with advanced cancer: a scoping review. *Acta Oncol* 2021; 60: 112–123.
32. Bourhis J. Narrative literature review. In: Allen M (ed.) *The SAGE encyclopedia of communication research methods*. Thousand Oaks, CA: SAGE, 2017, pp. 1076–1077.
33. Yee G and Yee F. *Methods of Patient & Public Engagement*. Winnipeg, Manitoba, Canada: Centre for Healthcare Innovation, 2020.
34. Sundhedsstyrelsen [Danish Health Authority]. *Indsatser mod ulighed i sundhed [Interventions against inequality in health]*. København: Afdelingen for Social Medicin, Institute for Folkesundhedsvidenskab, København Universitetet, 2020.
35. Sundhedsstyrelsen [Danish Health Authority]. *Ulighed i Sundhed – årsager og indsatser [Inequality in Health – causes and interventions]*. København: København Universitetet, 2011.
36. Green J and Thorogood N. *Qualitative methods for health research*. 2nd ed. London: SAGE, 2009.
37. Miles MB and Huberman MA. *Qualitative data analysis – an expanded sourcebook*. Thousand Oaks, CA; London; New Delhi: SAGE, 1994.
38. Riessman CK. Narrative analysis. In: Huberman MA and Miles MB (eds) *The qualitative researcher's companion*. Thousand Oaks, CA: SAGE, 2002.
39. Merrild CH. Social differences in health as a challenge to the Danish welfare state. In: Bendixsen S, Bringslid MB and Vike H (eds) *Egalitarianism in Scandinavia: historical and contemporary perspectives*. Cham: Springer International Publishing, 2018, pp. 181–200.
40. Hurst SA. Vulnerability in research and health care; describing the elephant in the room. *Bioethics* 2008; 22: 191–202.
41. Luna F. Elucidating the concept of vulnerability: layers not labels. *Int J Fem Approaches Bioeth* 2009; 2: 121–139.
42. Kipnis K. Vulnerability in research subjects: a bioethical taxonomy. In: National Bioethics Advisory Commission [NBAC]. *Ethical and Policy Issues in Research Involving Human Participants*. Rockville, MD: National Bioethics Advisory Commission [NBAC], 2001, pp. G1–G13.
43. Luna F. Identifying and evaluating layers of vulnerability – a way forward. *Dev World Bioeth* 2019; 19: 86–95.
44. Colmenares-Roa T, Figueroa-Perea JG, Pelcastre-Villafuerte B, *et al.* Vulnerability as a palimpsest: practices and public policy in a Mexican hospital setting. *Health (N Y)*. Epub ahead of print 19 January 2021. DOI: 10.1177/1363459320988879.
45. Bendixsen S, Bringslid MB and Vike H. Introduction: egalitarianism in a Scandinavian context. In: Bendixsen S, Bringslid MB and Vike H (eds) *Egalitarianism in Scandinavia: Historical and Contemporary Perspectives*. Cham: Springer International Publishing, 2018, pp. 1–44.