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**TRANSLATING PATIENT EXPERIENCES  
INTO CLINICAL PRACTICE**

AN EXAMPLE OF 'PATIENT INVOLVEMENT' FROM PSYCHOSOCIAL CANCER REHABILITATION IN DENMARK

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## KEYWORDS

*Patient involvement; patient experience; clinical practice; translation; cancer rehabilitation; institutionalism*

## ABSTRACT

*In this article we examine meanings and uses of the concept of patient involvement, using a psychosocial cancer rehabilitation intervention in Denmark as an example. Drawing on Scandinavian sociological institutionalism, we analyse the translation process of the concept and how it is understood, shaped and practised in four interrelated contexts: patients' experience of cancer care; a call for research bids to improve cancer care; a research project of psychosocial cancer rehabilitation; and the implementation of the project's intervention in clinical practice. Our analysis reveals distinct understandings and practices of patient involvement informed by the various actors' perspectives and the structures of the healthcare system. The meaning of patient involvement changed from patients seeking to engage in healthcare on their terms, to patients being expected by researchers and healthcare professionals to be 'active patients' in particular ways. Our analysis highlights the importance of critically examining the phenomenon of patient involvement in local contexts.*

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## INTRODUCTION

Patient involvement in healthcare is a complex concept that derived its initial impetus from the demands and activities of diverse social movements, and is now closely linked to a patients' rights agenda: patients' rights to safety, rights to information and choice, and their right to be heard (Longtin et al., 2010; WHO, 1994). At the same time, patient involvement is increasingly recognised as a key component in the redesign of healthcare processes, particularly in decision-making processes and care in chronic illness, although it can also refer to self-medication, self-monitoring, patient education, goal setting, or taking part in physical care (Jönsson, 2013; Longtin et al., 2010, p. 8; Ministeriet for Sundhed og Forebyggelse, 2014). However, patient involvement is not a well-defined concept and is often used interchangeably with overlapping terms such as patient participation, patient empowerment, patient engagement or patient centredness (European Commission, 2012; Longtin et al., 2010; Coulter, 2011). The concept of patient involvement in healthcare can therefore be suggested to express multiple – at times overlapping and at other times competing – perspectives: patients' desire for a more patient-orientated approach to care provision; liberal and gendered ideals, including an emphasis on personal behaviour and individual responsibility that underpins, for example, the Danish healthcare system; and support of changes in healthcare provision resulting from a neo-liberal political agenda (Vallgarda, 2007; Coulter, 2011). As Beresford (2002: 98) notes: "While the logic of the democratic approach is for 'user-led' or 'user-controlled' services, a consumerist approach is compatible with the retention of a provider-led approach to policy and services". Indeed, it can be argued that the uneasy and uneven blending of patients' rights and personal empowerment with managerialist and instrumentalist purposes, transforms patient involvement from a politics of patients' needs and demands into the administrative management of needs satisfaction (Fraser, 2013: 53-82).

In both European and Danish contexts it is argued that the involvement of individual patients and their relatives results in improved interaction and knowledge exchange between healthcare provider and patient, whereby '[t]he benefits of this are expected to be a better outcome for the patient' (European Commission, 2012: 14). A number of improved clinical outcomes related to patient involvement are noted in the literature, although it has also been argued that the links between patient involvement and clinical outcome tend to be weak and may be related to other unexamined variables (Street Jr., Makoul, Arora, & Epstein, 2009). Coulter (2012) suggests in a review that it is important to enable the active engagement of patients in planning and shaping their health care, and that their involvement in shared decision-making and improvement in quality tends to be beneficial. Patients who have received information about their treatment are said to comply more extensively with treatment regimes, are more satisfied with treatment, and achieve better results (VIBIS, 2015b); improving the health professionals' ability to accurately assess patients' preferences is expected to improve patient autonomy (Freil, 2014;

Jacobsen, 2008; Robinson & Thomson, 2001), as well as result in more patient-centred solutions and increased patient safety (VIBIS, 2015b). Accordingly, patient involvement is seen to obtain outcomes determined by healthcare professionals and related systems and is considered to be essential to improving the quality of healthcare (Foged, Schulze, & Freil, 2007). However, the concept of patient involvement is not well defined and no robust measurement to evaluate the impact of the delivery of such interventions exists (Staniszewska et al., 2011).

The Danish Patient Organisation (Danske Patienter) and the Knowledge Center for User Involvement in Healthcare<sup>1</sup> understand ‘patient involvement’ to entail two facets. Institutionally orientated patient involvement includes patients and relatives as representatives in fora concerned with the organisation, development and evaluation of the healthcare system (VIBIS, 2015a). By contrast – and our concern in this article – the involvement of individual patients (and their relatives) in their own healthcare focuses on patients’ (and their relatives’) engagement in and influence on the disease trajectory. This form of involvement comprises the sharing of knowledge about the patient’s disease and personal situation as well as being part of the planning and decision-making concerning her/his treatment and care (VIBIS, 2015a). That is, individual involvement emphasises active patients and relatives (Hansen, 2013; Moore, 2008). When patient involvement is predicated on an active and participatory role for patients (and relatives) to improve their well-being, it is less about the patient’s self-determination or the patient’s rights (Tritter, 2009); rather, it foregrounds outcomes determined by policy and the healthcare system, reflecting a concern with the responsibility for patient safety and minimising patient reliance on healthcare professionals.

Terminology is problematic, and it is important to acknowledge the different perspectives used in different arenas. In a multidisciplinary setting in particular, actors (health professionals, researchers and politicians) might use and understand the concept of patient involvement in various ways (Van Thiel & Stolk, 2013). The various terms and their definitions might indicate that disciplinary paradigms exert a strong influence on how different actors interact with patients, for example, or define a research project (Anderson & Funnell, 2005). The concept of patient involvement also resonates with related concepts such as participation, engagement, empowerment or patient centredness. Categorisations, typologies and classifications of participation and user involvement<sup>2</sup> abound (Brodie, Cowling & Nissen, 2009). They often seem to conflate theoretical concepts with practical activities, pointing to the need to examine local contexts in which the concepts are used and activities are carried out. We therefore suggest that in order to gain a nuanced understanding of the complexity of the concept of patient involvement and its meanings and practices, patient involvement needs to be investigated in particular circumstances and contexts. The aim of this paper is to examine how the concept of patient involvement is understood, shaped and practised in four interrelated contexts, and in so doing we seek to contribute towards a nuanced understanding of patient involvement in

the wider context of exploring citizen participation. Drawing on Scandinavian sociological institutionalism, we examine the shifting meanings and uses of the notion of patient involvement in relation to a psychosocial cancer rehabilitation intervention in Denmark, which aimed to facilitate the joint participation of patients and relatives. We specifically pay attention to actors and activities when the concept of patient involvement translates from one context into another.

#### A THEORETICAL PERSPECTIVE: TRANSLATION AND EDITING IN AN INSTITUTIONAL SETTING

To understand how ideas about patient involvement are adopted in health services research and integrated into hospital-based clinical practice, we draw on Scandinavian sociological institutionalism (Czarniawska & Joerges, 1996). Institutions, such as hospitals, are characterised by stable structures and routines, whereby hospital departments and health professionals filter and interpret ideas derived from an environment external to the institution through upholding stable routines, such as established clinical practices (Czarniawska & Sevón, 1996: 5).

We employ the concepts of ‘translation’ and ‘editing’ in particular. ‘Translation’ expresses how new ideas diffuse and are actively translated into a pre-existing context consisting of, for example, established ideas, actors, and knowledge before entering local practices. To be translated into a concrete practice and become realised, such external ideas require interpretation (Brunsson & Jacobsson, 2000: 145). From the perspective of hospitals, when changing an established clinical practice, health professionals must actively translate a new idea into their professional language, existing institutional structures, orders and artefacts in order to make the new idea fit (Latour, 1986 (in Sahlin & Wedlin, 2008)). For example, medical encounters between patients and nurses or patients and doctors constitute a common work routine for health professionals and reflect most patients’ expectations based on previous healthcare experience. Routines become taken-for-granted practices imbued with cultural meaning (Berger & Luckmann, 2004) and can be understood as stable social structures that give meaning to everyday activities.

‘Editing’ refers to the rules of how translation processes are guided and restricted by social control and traditionalism (Sahlin-Andersson, 1996). Based on the local context, editing rules implicitly and explicitly direct the translation process and guide how new meaning is created and ascribed to existing activities as well as how new activities with new meanings develop. For example, the gathering of information within the medical encounter is structured by requirements of biomedical knowledge, and can thus be understood as an ‘editing rule’ that guides and shapes the process of translating patient experiences into information usable by health professionals (Sahlin-Andersson, 1996).

## EXPLORING PATIENT INVOLVEMENT IN CANCER REHABILITATION: METHODS AND MATERIALS

The World Health Organisation (WHO) has defined rehabilitation as “the use of all means aimed at reducing the impact of disabling and handicapping conditions and at enabling people with disabilities to achieve optimal social integration” (WHO, 2001). In terms of the ICF model, rehabilitation can be defined as a coordinated process which enhances “activity” and “participation” (Hellbom, 2011). In Denmark the concept of cancer rehabilitation was introduced by the Danish Cancer Society in 1995 and later adopted by the National Cancer Plan I (Government of Denmark, 2000). According to this document, rehabilitation shall “provide to individual patients the knowledge, scope for action and support required for life to continue in the best possible way given the changes and limitations caused by the disease physically, psychologically, socially and existentially” (Government of Denmark, 2000, cited in Hansen & Tjørnhøj-Thomsen, 2008: 362). Cancer rehabilitation interventions in particular address psychosocial care, meeting other cancer survivors, information, education, and physical training (Hansen & Tjørnhøj-Thomsen, 2008). Public and private healthcare organisations and research institutions are getting involved in setting up cancer rehabilitation programmes aimed at helping cancer survivors to acquire a normal life. Part of the aim of cancer rehabilitation is for patients to be involved, actively participate in their illness trajectory, be able to have a say, and in this way shape their own lives. A cancer rehabilitation intervention can therefore be seen as an exemplary case suitable for exploring the concept of patient involvement.

To examine the phenomenon ‘patient involvement’ and how it is practised in various contexts, we use the example of psychosocial cancer rehabilitation as a single case study (Stake, 2005). The exploration of the translation process begins with a report on cancer patients’ experience and critique of existing cancer care provision followed by a call for research bids from the Danish Cancer Society. This is followed by exploring how this call was translated into a research project of cancer rehabilitation and then carried out in clinical practice in a hospital setting. Issues identified through the theoretical framework of institutionalism are used to choose and organise the data, and guide the analysis (Stake, 2005). The data used is derived from four sources and comprises information on local actors and their activities. The data sources contribute with information on actors and activities, and thereby data on how actors participate or are expected to participate in the identified contexts. The four data sources provide information on where the understanding of patient involvement and the subsequent idea of intervention came from, and how it became an intervention and was used in clinical practice. Data in four phases of a translation process:

*Phase 1:* The report ‘The world of the cancer patient’, published by Grønvold et al. 2006.

- Phase 2:* The call for research proposals, published by the Danish Cancer Society in 2008.<sup>3</sup>
- Phase 3:* A project proposal titled “Involvement of patients and relatives in the course of cancer disease with a particular view to rehabilitation and the life with cancer”, which was developed by a research group in 2009.
- Phase 4:* The research on ‘supportive talks’ from 2010-11, published by Ledderer et al. 2013, 2014.<sup>4</sup>

Framed by Scandinavian institutionalism (Sahlin & Wedlin, 2008), the analytical focus in examining our data is on actors and their perspectives, particularly their needs, expectations and demands in relation to patient involvement; the practices and meanings of patient involvement; and contexts, including patients’ previous treatment experience, health professionals’ clinical routines and institutional structures. We focus on how different actors in each phase of the translation process conceptualised, articulated and implemented – that is, translated - their understanding of the concept of patient involvement, and how the interplay between actors and contexts shaped different meanings as well as ‘edited’ the translation process from the report on patient needs through to the implementation of the ‘supportive talks’ in clinical practice. The four phases are elaborated and analysed in the following sections and the main findings are shown in fig.1.

#### PHASE 1. THE REPORT. ‘THE WORLD OF THE CANCER PATIENT’: GETTING TO KNOW PATIENT PERSPECTIVES

In 2006, a report by the Danish Cancer Society<sup>5</sup> revealed serious problems in the hospital care offered to cancer patients (Grønvold, 2006) and pointed out that the voices of the cancer patients and their relatives were not being heard, and that they were not being sufficiently involved in their own care. Key issues raised by patients concerned their problems in obtaining psychosocial cancer care; their feelings of being ignored as individuals; and a lack of care for and involvement of relatives. Patients experienced that there was not enough time for conversations and that the health professionals did not show enough interest in patients’ perspectives. Generally, patients evaluated the treatment received as good, but highlighted a need for more attention, to be treated as individuals and not numbers, and for their personal concerns to be taken seriously. Moreover, one third of the patients felt that health professionals did not show an interest in the relatives and the ability of the relatives to manage daily life together with a seriously ill person. To address these experiences, patients asked for more psychosocial support (care, interest, being heard and taken seriously) from health professionals. The report pointed to a need to actively involve cancer patients in healthcare and that any proposed solution should focus on ‘partnerships’. This can be said to reflect the above noted research findings which argue that involving patients and relatives improves treatment and care. At the time of the report, no systematic rehabilitation programmes addressing the needs of both patients

and relatives existed in Denmark. The report brought forward the patients' demands for more time for conversation and a recognition of the needs of both patients and relatives. New ideas from patients and patients' organisations framed the topic of translation and directed the process of translation (Sahlin & Wedlin, 2008: 225). The notion of the 'active patient' includes patient needs and experiences to be present in the planning, development, implementation and evaluation of future intervention in healthcare provision. This resonates with what Beresford (2002) characterises as the democratic approach to patient involvement that is 'rooted in people's *lives* and in their aspirations to improve the nature and conditions of their lives' and is concerned with 'ensuring that participants have the direct capacity and opportunity to make change' (p. 97; italics in original).

## PHASE 2. A CALL FOR RESEARCH BIDS BY THE DANISH CANCER SOCIETY: RESPONDING TO THE PERSPECTIVES OF CANCER PATIENTS

As a result of the public attention following the publication of the above report, financial resources were allocated, including research funding by the Danish Cancer Society, to support the development of psychosocial cancer rehabilitation which jointly involved patients and relatives. In the following, we examine the call for research bids; and in so doing we explore the second phase of translating cancer patients' demands and concerns.

The call for research bids published by the Danish Cancer Society highlights how the Danish Cancer Society interpreted the above report's results as a particular kind of lack of user involvement in clinical care. The call states: 'It is of great importance that healthcare organisations and health professionals ensure good information exchange and communication with patients and that patients are heard, respected and met as human beings with individual needs. The healthcare system must increase its focus on patient-centred healthcare where patients formulate their own needs and make their own choices.' In this way, the Danish Cancer Society's understanding of patient involvement is aligned with the approaches adopted by the European Commission and VIBIS noted above, whereby patients have a central position in their own illness trajectory in terms of, for example, treatment planning and decision-making. This understanding, it can be suggested, also resonates with a neo-liberal agenda of choice (Vallgarda, 2007) rather than care (Mol, 2008).

To place the patient (and relatives) into the centre of attention in this particular way, the call focused on three themes: 'Patient Partnership', 'The World of Relatives', and 'Dialogue and Communication'. Reflecting some of the concerns expressed by cancer patients (Grønvold, 2006), research related to these themes aimed to achieve the following: 1) improve the experiences of care for patients and relatives through the provision of psychosocial support involving patients and relatives; 2) generate knowledge about the involvement of patients and relatives in psychosocial cancer care; and 3) improve dialogue and communication between patients, relatives and health professionals. The



call explicitly invited projects that addressed the relationship between patients and relatives, actively involved patients and relatives, and included relatives in treatment, care and rehabilitation for patients. In addition, new programmes were required to develop clinical interventions that measured effects on patients' and relatives' quality of life, and could be generalised to a broader context. However, it did not specifically address the roles of patients and their relatives in future research interventions.

The call was highly influenced by the concerns of cancer patients made public in 2006 (Grønvold, 2006), together with emerging ideas and claims about the benefits and outcomes of patient involvement in healthcare originating largely from Anglophone countries, which were noted earlier. In deploying the emergent concept of 'patient involvement', the call legitimised specific research areas and methods. These reflect a tension between, on the one hand, the demand of patients and relatives for individualised psychosocial care and their active involvement in their healthcare which was also noticeable in health and social movements, and, on the other hand, the requirements of evidence-based clinical practice based on proof of efficacy, effectiveness and generalisability of outcomes. Indeed, these tensions echo the hybridity of the constituency, mission and vision of the Danish Cancer Society and it could be interpreted as a tension between participation in democratic models and patient choice in consumerist models (Tritter, 2009).

Furthermore, the call asked for a specific way for patients and relatives to participate in healthcare; that is, as an active patient who is engaged in her/his own healthcare, supported by equally active relatives who are able and interested in participation. For example, the call emphasised the importance to 'activate the individual patient in her/his own disease trajectory' and 'to strengthen patients' capabilities through active empowerment so as to be able to manage everyday life with chronic disease'. It further stressed 'the needs and possibilities to engage relatives more actively in the treatment and healthcare of patients'. That is, with its emphasis on active patients and relatives, the call pointed to what is seen as appropriate and desirable behaviour in healthcare (Hansen, 2013; Moore, 2008).

It can therefore be argued that through this call for research bids, specific understandings and forms of patient involvement were translated into a new local setting with distinct practices, whereby the understanding of patient involvement was interpreted and transformed by the local actors, in this case the Danish Cancer Society. How the demands of the call were taken up in the third phase, the resulting research project, is turned to next.

### PHASE 3. TRANSLATING THE CALL FOR RESEARCH BIDS INTO A RESEARCH STUDY: DEVELOPING A STUDY PROTOCOL

To respond to the call, a research group was established that included physicians and nurses from two surgical departments specialising in cancer treatment, and university-

based researchers with a background in health services research and psychosocial cancer rehabilitation. Focusing on the call's themes of 'Patient Partnership' and 'The World of Relatives', the research group translated the idea of patient involvement presented in the Cancer Society's call for research bids into a study protocol, including a clinical intervention as part of the research project. That is, the idea of patient involvement as presented by the Danish Cancer Society is concretised into discreet research activities. These activities reflect the third phase in the translation process from patients' perspectives about existing cancer rehabilitation provision into clinical practice (Sahlin & Wedlin, 2008). In this phase a tension between patient involvement in the research process and patients' involvement in making choices, decisions and participating in healthcare practice become visible as patients (and relatives) were not involved in the first process but were expected to assume an active role in the illness trajectory.

The study developed by the research team used a randomised clinical trial (RCT) design supplemented by qualitative components; it was carried out in 2010–11 and involved 42 patients and relatives (Ledderer et al., 2013). The intervention investigated by the study targeted interpersonal communication between a patient and a relative, everyday life issues and social relationships (Ledderer, la Cour & Hansen, 2014; la Cour, Ledderer & Hansen, 2015), and comprised two components: 1) Three sessions of 'supportive talks' between a patient, a relative and a nurse. These sessions were carried out within the first two months from the day of hospital admission and were held at the hospital; 2) a one-week residential rehabilitation course (9 months after hospital admission) held at a rehabilitation centre. The facilitation of all activities was planned and carried out by healthcare professionals (e.g. nurses, social workers, dieticians, psychologists) who were experienced in cancer treatment and cancer rehabilitation. The health professionals' ideas for intervention activities were derived from their clinical practice and were based on their professional knowledge and assumptions of patients' needs. Although evidence from other research studies was included in the protocol, which at that time was sparse with regard to the involvement of relatives, the research group only indirectly included patients' voices in the design, planning and implementation of the cancer rehabilitation intervention.

The study reflected the researchers' and healthcare professionals' understandings of an appropriate research design and associated interventions, building on perceptions of how and when patients and relatives should be included in patients' cancer rehabilitation. That is, the health professionals' background knowledge about patients and the demands of evidence-based research and medicine can be understood as editing rules that further directed the concept of patient involvement, underpinning the call for research bids and their implementation into the research study. The understanding of appropriate healthcare by professionals and researchers informed the form, content and values of the intervention (Sahlin & Wedlin, 2008), and made them fit into the usual clinical practices (Czarniawska & Sevón, 1996). Given the results of the 2006 report (Grønvold, 2006), it

seems that in developing the research design, the researchers and healthcare professionals made a number of assumptions: that patients and/or relatives were in need of psychosocial support as perceived by health professionals; that patients and/or relatives desired to be involved as early as possible (i.e. from the day of admission); and that they were ready to interact with healthcare professionals regarding their future illness trajectory as a way of coping with distress and discomfort resulting from the cancer diagnosis and any treatment. Accordingly, in the intervention of ‘supportive talks’, patients and relatives were to be informed and explicitly asked about their needs and worries, presupposing that both patients and relatives were able, interested, and prepared to take the opportunity to play an active role in managing the illness and its treatment. Thus, with its focus on complementary activities involving patients and relatives, the intervention design affirmed and consolidated an understanding of patient involvement predicated on active participation as desirable healthcare behaviour for both patients and relatives (Hansen, 2013; Moore, 2008). In this way, patient involvement as signifying the active patient (and relative) was to be translated into the hospital context.

At the same time, patients’ and relatives’ knowledge, interests and understanding of their situation and experiences were excluded, as they were not involved in the research process, for example, in the conceptualisation and development of ‘supportive talks’ or other interventions. This lack of direct patient input in shaping the intervention may reflect an attitude of healthcare professionals and researchers alike, that ‘healthcare professionals know best’, and is not recommended in the review by Coulter (2012). This, in turn, may have further contributed to a specific understanding of patient involvement and its translation into clinical practice. To further analyse how patient involvement was understood and carried out in a hospital setting, and how a specific form of participation was encouraged through the intervention, we turn to discussing the fourth phase which describes how patient involvement was enacted in ‘supportive talks’.

#### PHASE 4. TRANSLATING PATIENT INVOLVEMENT INTO CLINICAL PRACTICE: THE CONTENT, FORM AND ORGANISATION OF SUPPORTIVE TALKS

As mentioned earlier, the supportive talks aimed to respond to cancer patients’ demands to address the needs of both patients and relatives. The supportive talks constituted an essential part of the intervention and introduced a new clinical practice into the hospital department. Clinicians and researchers assumed that patients’ needs for psychosocial support started from the moment of receiving a cancer diagnosis and the talks, therefore, were initiated on the day of admission. In this way the project carried forward a perception that health professionals know best and are able to assess patients’ needs and participation preferences without directly having asked them. However, during the study period it became clear that the professionals’ ideas and the existing hospital structure did not meet the needs of all patients and relatives. Several of the study participants – both

patients and relatives – reported that they would have preferred to plan the time schedule of their supportive talks themselves (Ledderer, la Cour & Hansen, 2014: 226), a possibility which might have increased participants' autonomy and their involvement in shaping their healthcare.

The supportive talks were intended to differ substantially from both the admission interview and the medical interview: the admission interview structures documentation of patient information in nursing care, while the medical interview is one of the physician's diagnostic tools. By contrast, the supportive talks were designed to initiate a conversation that focused on interpersonal communication, the relationship between patient and relative, and on increasing their mutual understanding. That is, the supportive talks aimed to give patients and relatives an opportunity to discuss everyday life issues; for example, domestic practicalities, work situations, or emotional issues. To support the nurses facilitating the talks, the research group and the clinical staff developed a topic guide comprised of five themes: 1) presentation of patient (relative) and the illness trajectory; 2) expectations of the hospital and staff; 3) expectations of each other and family/friends; 4) feelings and emotions; and 5) everyday life. The guide was understood to be flexible, in order to allow patients and relatives to determine the issues most relevant to their personal situation.

However well intentioned, the format and content of the supportive talks raises several issues: foremost is an apparent assumption that all patients and relatives would want and be able to participate actively in making treatment decisions, and shaping their illness trajectory from the point of diagnosis. While this may reflect values of personal behaviour and individual responsibility (Vallgarda, 2007), not all patients and relatives may subscribe to or be able to fulfil these aspirations.

Similar to the above process of identifying intervention activities and their timing, patients (and relatives) were not involved in developing the topic guide. Rather, the content of the supportive talks derived from prior literature searches and focus group discussions with health professionals, which identified the patient's need for discussing interpersonal communication and everyday life issues during hospitalisation. The supportive talks can therefore be interpreted as one form of the health professionals' understanding of patient involvement; an understanding predicated on a normative ideal of an active patient and an active relative (Hansen, 2013; Moore, 2008), and translated into a hospital setting in this particular way.

The supportive talks were, however, not only shaped by a particular interpretation of patient involvement, but also by the hospital setting and the common understanding of activities within its organisation, such as admission and medical interviews. In the context of supportive talks, the routine activities of admission and medical interviews provided a familiar pattern of action, which directed and restricted the process of translation by editing rules (Sahlin & Wedlin, 2008: 225). In the new encounters of patient, relative and nurse, both patients and relatives were invited to participate equally, and despite the

existence of a topic guide for use by nurses, the subjects for discussion were open to being guided by patients and relatives. This dynamic of introducing new intentions, patterns of action and meaning into existing routines is the active process of change (Sahlin & Wedlin, 2008: 224).

The translation of 'patient involvement' into the prevailing routines indicates that the hospital setting also provided valuable resources, which patients and relatives could draw on. For example, trained nurses were available for questions, discussions and emotional support, and the inclusion of the supportive talks at the point of hospital admission facilitated an early discussion of any concerns related to the cancer diagnosis and treatment, which might be held by patients and relatives. This seemed much appreciated by many of the participants in the study (Ledderer, la Cour & Hansen, 2014).

On the other hand, the supportive talks also upheld the importance of medical expertise; for example, nurses experienced in cancer care facilitated the conversations between patients and relatives, and the topic guide was developed by health professionals. Accordingly, some patients and relatives considered the supportive talks to be another occasion of receiving information concerning the cancer diagnosis, treatment, and routine care at the surgical ward. In this instance, the intended purpose of supportive talks faded into the background and medical information became central. As such, the supportive talks were transformed by the hospital's editing rules and translated into what can be described as 'supportive medical talks' appropriate to clinical practice in a hospital setting (Sahlin & Wedlin, 2008). In this way, these talks were adapted to the existing institutional logic that demands participation in existing routines, although these may be ascribed new meaning; in this case, 'patient involvement'.

Established hospital routines further contributed to the editing of the supportive talks, particularly in relation to the active involvement of relatives. The supportive talks, beginning with hospital admission and taking place during hospitalisation, were always conducted during the daytime. This made it impossible for some relatives to join due to their own working hours. Thus the translation of the intervention from research proposal into clinical practice in a hospital setting reveals the normative ideal of the active relative who is assumed to be able and available to support an ill family member at all times. In addition, the usual routines of the hospital department take place predominantly during the day. These routines are determined by the need for surgical treatment and care. The first supportive talk was to be conducted shortly after admission, but the intended time for supportive talks competed with required medical examinations and investigations, and information dissemination about surgery and treatment. The health professionals experienced this as a tension because it was difficult to plan and conduct supportive talks at the same time as 'ordinary' healthcare tasks (Ledderer, la Cour & Hansen, 2014: 227). The existing organisational routines prioritised clinical work over supportive talks, and if they were to be embedded into clinical practice, new routines with different forms, content and values would have to be created (Anderson & Funnell, 2005; Sahlin & Wedlin,

2008). It resonates what Beresford (2002) characterises as the consumerist approach to participation that ‘starts with policy and the *service system*’ (p. 97; italics in original) and is managerialist and instrumental in purpose.

## CONCLUSION

Drawing on the example of a psychosocial cancer rehabilitation intervention in Denmark, the analysis of meanings and practices of ‘patient involvement’ presented reveals considerable diversity. The analysis reveals changing understandings and practices of ‘patient involvement’ as the concept is translated from one phase into another, following the pre-existing, general rules and understandings of healthcare in patient-, research- and healthcare organisations. During the translation process the meaning of ‘patient involvement’ changed, shifting from patients (and relatives) seeking to engage in healthcare on their terms, to patients (and relatives) being expected by healthcare professionals and the healthcare system to be ‘active patients’ (and relatives) in particular ways. Following Beresford (2002), both the democratic and consumerist approaches may be concerned with producing change and influencing what and how things are done. Our analysis, however, demonstrates that the new practice of patient involvement in the form of ‘supportive talks’ was transformed to fit into the hospital setting. In this way, we suggest, the experience of patients and their demand for self-determination and involvement was met with only a slightly new practice in the clinical context, whereby the new practice takes on the form, content and value of the service system. A number of aspects are shown to shape the translation process, including different actors’ demands, expectations, needs, and understandings of the concept of patient involvement. The identified diversity is further shaped by normative assumptions about appropriate healthcare behaviour and specific local institutional contexts, which contribute to how the translation process is edited in the different contexts. The call for research bids by the Danish Cancer Society and the subsequent development of the intervention by the research team de-emphasised specific organisational settings. The significance of local actors and settings on the understandings, practice and meanings of patient involvement comes to the fore, however, when the four phases of the translation process and its editing of user involvement are considered specifically. These highlight significant differences and priorities in understanding the concept of patient involvement, its practices and meanings, and point to the importance of critically examining the phenomenon of patient involvement in local contexts.

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## NOTES

- 1 The Danish Patient organisation (Danske Patienter) is an umbrella organisation of 17 Danish patient organisations. The Knowledge Center for User Involvement in Healthcare (VIBIS) was established by The Danish Patient organisation in 2011 with the aim to collect, develop and disseminate knowledge about the involvement of patients and relatives in the healthcare system
- 2 A note on terminology: We use the terms 'participation' and 'involvement' interchangeably; when referring in general terms to participation, we use the term 'user', while the term 'patient' is used in the healthcare context.
- 3 The call for research is not available electronically.
- 4 The first author was part of the research team that implemented the study in 2010-2011 at the Odense University Hospital, Denmark.
- 5 Danish physicians started a medical cancer organization in 1924. The organization became The Cancer Society in 1928 and is today one of the largest member organizations in Denmark. In 2013 it had a membership of 455,194 and a turnover of 622.9 million Danish kroner. The organization is professionally run and organized; medical professionals constitute an integral part of the management and directorate. Research topics supported by the organization include palliative effort, care, relations between patient and doctor, relatives, children and youngsters, research in behaviour, ethics and structure and function in the public health system in relation to cancer. <http://www.cancer.dk/om-os>

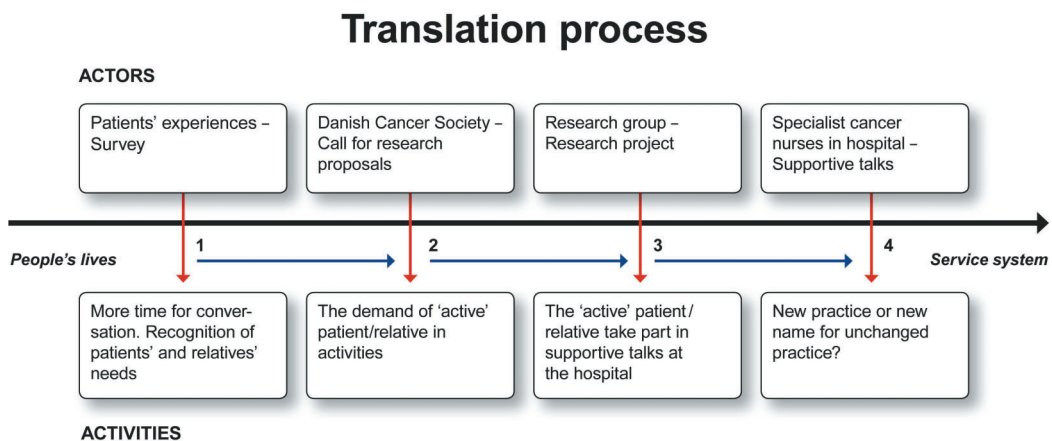


Fig 1. The translation of patient involvement in four phases: From patients' experiences into clinical practice