Original article

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Theoretical perspectives and qualitative designs in research on patient participation

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Over time, research on patient participation has evolved from describing interactions between patients and health professionals to also include the importance of social and structural factors for patient participation. This requires researchers to use different research designs when they want to study this, both qualitative and quantitative. Narrative, social constructivism, critical discourse analysis, hermeneutics, phenomenology and grounded theory are qualitative designs that are often used to illuminate various aspects of patient participation. Different professions must develop a common frame of reference in an area where cooperation is important for success, and it is therefore valuable to have interdisciplinary and interprofessional approaches in further research in the field.

Patient participation is an international field of research. Different definitions and theories have been developed to understand the concept, and different designs have been used to research the area. This article presents theoretical perspectives on patient participation and five qualitative designs used in international research. Qualitative design includes both methodology and method. Methodology deals with the underlying theoretical thought behind science and philosophical premises for various designs, such as hermeneutics. Methods deal with specific procedures such as interviews to collect data (Creswell & Creswell 2018).

Theoretical perspectives

Extensive research has been conducted clarifying the content of the concept of patient participation (Cahill 1996; Thompson et al. 2007; Arnstein, 1969; Castro et al. 2016; Sahlsten et al. 2007). In the research literature, it is seen that the terms patient participation, patient involvement, patient and user participation are used synonymously (Castro et al. 2016). Patient participation can be understood at the micro (individual treatment), meso (organisational level of the health service), and at the macro level (health policy) (Castro et al. 2016).

The first person to develop a framework for patient participation was an American social scientist and researcher, Sherry Phyllis Arnstein (1969), with the so-called 'ladder of citizen participation'. It shows various steps for participation ranging from manipulation by health professionals to the patient having power over the situation. The higher up the ladder, the more patient participation.

English nurse and researcher, Jo Cahill (1996: 365), conducted a systematic conceptual analysis of patient participation in a nursing context in the mid-1990s. Five characteristics for achieving participation were highlighted: (1) there must be an established relationship, (2) relevant information must be given and knowledge and/or competence gaps must be handled with the help of suitable modalities in different contexts, (3) there must be a surrendering of a degree of power or control by the nurse, (4) there must be engagement in selective intellectual and/or physical activities during some of the phases of the health care process and (5) patients must experience the activities as valuable. Cahill has been an important contributor in creating an understanding of patient participation as a concept, both in research and clinical work.

Swedish nurse and researcher, Monika Sahlsten and colleagues, conducted a systematic conceptual analysis of patient participation in the late 2000s (Sahlsten et al. 2008) - clearly inspired by Cahill (1996). She further defines the content of patient participation as an established relationship between patient and nurse, that participation involves surrendering of a degree of power or control by the nurse, and that information and knowledge is shared, and that common engagement in treatment-related activities exists. Sahlsten and colleagues (2008) argue that this definition can be useful in assessing how patient participation is designed, implemented and how it can be evaluated. This understanding also highlights important qualities, such as the patient-centered approach and continuity in care. Consideration of the patient's experience and having respect for the patient's choices are also emphasised.

In the mid-2010s, Belgian social scientist and researcher, Eva Marie Castro and colleagues, carried out a systematic analysis of the concept of patient participation (Castro et al. 2016). Based on the last step in the concept analysis, a literature review, Castro and colleagues propose the following definition of patient participation: "Individual patient participation is about the patient's rights and opportunities to influence and engage in the decision-making about their own care through a dialogue attuned to his or her preferences, potential and a combination of his or her experiential and the professional expert's knowledge. Collective patient participation is about the patient's or patient organisations' participation in the design of health and social care services by involvement in a range of activities at the individual, organisational and political levels combining experience and professional knowledge" (Castro et al. 2016: 1929).

Both Cahill (1996) and Sahlsten and colleagues (2008) emphasise an individual and clinical perspective on participation in their definitions. The contextual relationship is not affected. On the other hand, the definition of Castro and colleagues (2016) has been extended to also include participation at the organisational and political level.

Theoretical model on patient participation

A key public policy and citizenship researcher from Scotland, who has made theoretical contributions to understanding patient participation, is Andrew Thompson (2007). He describes several levels of participation in a taxonomy that illustrates different degrees of participation; (1) autonomous decisions, (2) shared decisions, (3) being given information and engaging in dialogue, (4) seeking information and receiving information, and (5) not being involved. The taxonomy describes patient power as ranging from exclusion from decision-making to co-determination of treatment, in other words from a paternalistic approach to an equal dialogue. It has been argued that this model may give a basic understanding of patient participation in different contexts (Thompson 2007).

Thompson and colleagues have also been involved in developing a holistic theoretical framework for understanding patient participation (Thompson et al. 2007). The framework is intended to reflect the complexity of the phenomenon. Patient participation can be understood in terms of components, levels and contexts. Important components of participation are: (1) influencing the choice of action, (2) participation in the definition of the problem, (3) participation in reasoning processes about treatment, (4) involvement in decision-making, and (5) mutual emotional encounters (Thompson et al. 2007). This framework highlights the complexity of participation, i.e., that participation must be understood from dissimilar patient situations, and will therefore unfold differently in dissimilar patient pathways.

Several researchers in the field of nursing, pedagogy and social medicine have used the framework to analyse patient participation for various patient groups in clinical situations (Kvangarsnes et al. 2013a; Rise et al. 2012;

Andersen-Hollekim et al. 2019; Aasen et al. 2012b; Bårdsgjerde et al. 2019). This model highlights the interaction between the patient and health professionals. The model does not address participation of relatives and patients at system level; however, the model has been used to highlight the involvement of relatives in palliative care and haemodialysis (Tarberg et al. 2019; Aasen et al. 2012c)

Qualitative design

Narrative approach

The word narrative comes from Latin 'narrare' which means to tell. A story often has a course of events. Narrative design could be one way to study the patient's experiences of participation in a patient pathway. This approach gives patients a clear voice. By highlighting patients' perceptions of participation, health professionals can gain a new and changed understanding of the patient's situation and how patients and relatives have experienced and view participation (Chase 2018). Narrative analysis has different theoretical directions that capture personal and human dimensions of experience over time taking into account the relationship between individual experience and cultural context (Clandinin & Connelly 2000).

The term patient participation can be perceived as theoretical and distant, and it may therefore be appropriate to use a narrative form of interview when examining personal experiences related to participation in illness and treatment. In a narrative interview, open-ended questions are used to invite the telling of personal experiences with involvement in the patient process (Brinkmann & Kvale 2015).

There are many understandings of narrative research and the definition of narrative has changed over time. American sociologist and researcher, Susan E. Chase (2018), describes a development from which narrative was exclusively used to illuminate the past and present to inclusion of the future in narrative presentations. Narrative may be an appropriate way to study participation in a patient pathway, as patient pathways have a time perspective and chronology of events.

The selection of informants in narrative research is often strategic and aims to capture the complexity of participation from the patient perspective. The narrative can be based on experiences from one patient but also from several (Brinkmann & Kvale 2015). When you have several informants, the interviews are presented as one narrative, which represents an interpretation of all the patients' stories. The stories can also be obtained with the help of documents or texts from, for example, letters and diaries (see Table 1).

In narrative analysis, one searches for a plot which is a pattern of developments in the stories. The plot may, for example, describe participation in different phases of a patient pathway (Holloway & Freshwater 2007; Patton 2015). Fundamental questions in narrative research are: (1) What theoretical framework is the study based on? (2) What type of knowledge do personal narratives give us access to? (3) What ethical position does the researcher hold in the presentation of data? (4) What methods should be used to produce narrative data? (Thomas 2010). Explicitness about the underlying choices taken is important for the credibility of narrative research (Chase 2018).

Narrative approaches have proven valuable in illuminating both the patients' and relatives' experiences of involvement in patient pathways (Tarberg et al. 2019; Kvangarsnes et al. 2013b; Bårdsgjerde et al. 2019). The narratives give the informants a clear voice and give access to personal experiences that can provide a deeper understanding of participation.

Social constructivist approach

Social constructivism is based on a fundamental understanding that all human cognition is socially constructed (Berger & Luckmann 2000; Mead et al. 2015). Knowledge is a result of culture, and the historical and contemporary context of which the individual is a part (Howell 2013). There are many fields within social constructivism, but the common denominator is an emphasis on the importance of social factors. The various fields are rooted in pedagogy, sociology, linguistics, philosophy and the social sciences. This interdisciplinary approach has gained great importance in many academic environments and has contributed to theory development.

Social constructivist theory and methods may provide a holistic understanding of a field of research and pave the way to understanding patient participation as a social negotiation process. The approach may provide insight into how participation is constructed in practice and provide valuable knowledge for implementing patient participation, as set out in legislation and guidelines.

With the aid of image analysis and social constructivist theory, Norwegian nurses and researchers, Ingrid Christina Foss and Marit Kirkevold (2008), have analysed patient participation from a gender perspective. The approach provides an opportunity to uncover underlying and implicit expressions about patient participation. This knowledge is valuable for raising awareness with a view to creating change.

Critical discourse analysis

Critical discourse analysis is a research strategy, whereby the purpose is to analyse how language contributes to creating and maintaining power structures (Fairclough 1992). The research strategy aims to uncover underlying power structures in texts to create change. By performing in-depth text analyses and taking into account the social and historical context in which the text is included, this approach allows one to highlight how society's hierarchies of power are created and reproduced through discursive practice.

Patient participation is about the distribution of power between patients and health professionals (Thompson 2007). Critical discourse analysis may provide insight into how the patient's right to participation is safeguarded in various contexts. Internationally, the right of patients to participate in treatment has been strengthened (WHO 2013). In Norway, the patient participation perspective was already evident in the National Health Plan (2007 - 2010) (Ministry of Health and Care Services 2009a). It was stipulated that users should be involved in the shaping of all parts of the health service. In the Coordination Reform, this perspective was continued and strengthened (Ministry of Health and Care Services 2009b). It is important to study how the legislation on patient participation is implemented in clinical work, at system level and in the formulation of national guidelines for treatment. An evaluation of how patients, relatives and earlier patients of the health service in Norway participated in work on the formulation of 127 clinical guidelines (2000–2009), showed disappointing results (Røsvik et al. 2010). With a few exceptions, patients had not participated in the development of the guidelines examined. In the guidelines, few attempts were made to include patients' views by using literature searches for updated research on patients' needs. Systematic collection of information from patient organisations was not carried out either.

Critical discourse analysis can be useful for analysing how the democratic intentions in legislation are taken care of at the micro, meso and macro levels. By connecting the different levels, it is possible to gain an increased understanding of the discourse on patient participation in a society (Fairclough 2001).

Critical discourse analysis is based on a discursive event, which is the use of language in a specific situation (Fairclough 1992). Analyses at three levels are carried out: (1) text analysis (for example, word choice, sentence level, modalities), (2) discursive practice (production of text, distribution processes and how a text is consumed) and (3) discourse as social practice: ideology and hegemony (discourse is placed in an understanding of power).

Critical discourse analysis is about analysing the relationship between text, interaction and context (Fairclough 1992). Several researchers have been inspired by English researcher and linguist, Norman Fairclough, when studying patient participation in clinical activities in acute and chronic disease (Aasen et al. 2012a; Kvangarsnes et al. 2013a). These studies show the value of combining text analysis and analysis of discursive practice with theoretical models of patient participation. The studies highlight ethical dilemmas in treatment in both acute and chronic situations. Value-laden words and expressions, metaphors and modalities in language, highlighted underlying power structures and lack of participation in the treatment (Aasen et al. 2012b; Kvangarsnes et al. 2013a). Contradictions were uncovered between the rhetoric in health policy documents and the experiences of patients and health professionals with patient participation.

Hermeneutic approach

Hermeneutics is about the interpretation of texts. Etymologically, the word comes from Greek 'hermeneuein', which means to express in the sense of conveying and speaking. Interpretation and explanation also fall under hermeneutics, as does translating from one language to another. Thus, the word has a threefold meaning: to express, to interpret and to translate (Gulddal & Møller 1999).

Hermeneutics has evolved from antiquity with dialogue as an ideal for cognition. Philosophers, Friedrich Schleiermacher (1758–1834), Wilhelm Dilthey (1833–1911), Martin Heidegger (1889–1976), Hans-Georg Gadamer (1900–2002) and sociologists, Jürgen Habermas (1929) and Paul Ricoeur (1913–2005), have been important contributors in the development of hermeneutics into a philosophy of understanding (Gulddal & Møller 1999). Many consider hermeneutics to be the most important theory of science in the humanities. A key concept in hermeneutics is the hermeneutic circle. This refers to the idea that the understanding of a text as a whole is based on the understanding of each individual part. Interpretation becomes a process that oscillates between parts and the overall context in which the part exists.

Gadamer (1999) emphasised the importance of prejudice for understanding. Prejudice is part of the human horizon of understanding and is as such an important gateway to interpretation and understanding. Separating valid prejudices from the invalid ones is a challenge. This must be tested in dialogue with the past, i.e., examine how one previously looked at a case. The interpreter's pre-understanding must be tested with the help of time intervals, consequently, it is changed and adjusted in the light of new experiences.

Gadamer conveys that the time interval often makes it possible to solve the critical questions of hermeneutics, the separation of the true prejudices that make us understand from the false ones that make us misunderstand (Gadamer 1999). Understanding begins when something speaks to us. We question texts that include historical thinking where we also include an understanding of our own historicity. Gadamer's texts on understanding have later been criticised, nuanced and problematised by, among others, Habermas (1999). A hermeneutic understanding is developed by the interpreter listening to the text and asking questions to interpret the underlying meaning. The goal is to gain a deeper understanding than what the text inherently expresses. The text must be interpreted in a historical and cultural context. The researcher must listen to the text with empathy and seek underlying opinions. The art is to bring out what is not in the text (Marquard 1999).

Underlying principles in hermeneutic interpretation have been presented as: (1) interpretation should have a logical context, (2) overview of the totality of the work, (3) underlying problems must emerge, (4) all the questions that the text raises must be answered, (5) the questions must come from the text and not from the interpreter, (6) the text must be interpreted in a historical and cultural context, (7) the interpreter must respect what the author says, (8) the interpreter must respect established interpretations of text, (9) the interpretation must stimulate further thinking, and (10) the interpretation can be transferred to other areas (Alvesson and Sköldberg 2009).

Professor of philosophy, cultural scientist and researcher at the University of Bergen, Nils Gilje, also points out that different hermeneutic traditions may be perceived as incompatible. Nevertheless, they can unite in specific research projects and draw benefits from each other (Gilje 2019).

Hermeneutic approaches have been used in studies of patient involvement in chronic disease. An example is nurse and researcher, Tone E. Hollekim-Andersen and colleagues (2019), who have studied the experiences of nurses with patient involvement in haemodialysis treatment. An important finding was that participation varied in different phases of the patient pathway. Acute treatment might lead to a small degree of participation. The treatment context was considered to be of great importance for the participation. The family's absence in treatment planning was also an interesting finding (Andersen-Hollekim et al. 2019). The study shows how a hermeneutic approach can be valuable in gaining insight into how the treatment context and the patient's disease state can provide important premises for involvement in the patient pathway.

Phenomenological approach

Phenomenology has had a great influence on research in the health sciences, especially in nursing. Eva Gjengedal (1994) and Kari Martinsen (2003) are Norwegian nurses and researchers who have developed and promoted this tradition in their field. The research tradition is closely related to the experiences of patients and health professionals in practice. Therefore, it is relevant to understanding the perceptions of patients, relatives and healthcare professionals of involvement (Jones et al. 2012). In phenomenology, the world in which we live, and with which we have immediate familiarity and experience, is called the 'life-world' (Husserl 1965). German philosopher, Edmund Husserl, argues that knowledge has a validity regardless of when and by whom it is formulated. Husserl's point of departure is that the world can be nothing other than the world as it appears in our consciousness. The concept of the life-world does not take into account power relationships in society, i.e., social conflicts and conflicts of interest between different groups (Crossley 1996).

Gjengedal (1994) has conducted a phenomenological study of the experiences of patients and health professionals with treatment of critical illness. The study provided important insight into the vulnerability of intensive care patients during respirator treatment. Norwegian nurses and researchers, Henny Torheim & Marit Kvangarsnes (Torheim & Kvangarsnes 2014), based their study on the phenomenological philosophy of Norwegian nurse and researcher, Kari Martinsen (2003). The study has helped to create an understanding of patients' vulnerability during interaction and involvement with health professionals in acute treatment of chronic obstructive pulmonary disease.

Grounded theory

Grounded theory can be considered both as a qualitative design and as a method for developing new and context-specific theories (Starrin 1996). Grounded theory is a widely used qualitative concept in international research (Morse et al. 2009). Grounded theory includes and translates quantitative concepts, such as validity, reliability, causality and generalisability to qualitative research and is therefore considered to be a systematic and contextual method (Bryant & Charmaz 2007).

Grounded theory was developed by American researchers, Barney Glaser & Anselm Strauss (1967). Glaser was educated in advanced quantitative analysis at the University of Colombia, while Strauss was educated in qualitative methodology and field-related research at the University of Chicago. Glaser & Strauss (1967) developed a systematic method containing both qualitative and quantitative elements that allow data to be moved to theory (induction) to create alternative theories. Such theories will be related to the context in which they are developed. The foundation of grounded theory is based on observations rather than on pre-defined analytical constructs, categories or variables from already established theories. The theory emerges from the substantial field of research (Starrin and Svensson, 1996).

Grounded theory consists of eight prominent phases or concepts (Willig 2013): (1) categories (groupings of cases), (2) coding (the categories are identified), (3) constant comparative analysis (identification of similarities and dissimilarities between categories), (4) negative case analysis (development of theory in light of current evidence), (5) theoretical sensitivity (from a descriptive to analytical level), (6) theoretical sampling (collecting additional data based on categories that have emerged in previous phases of the data analysis), (7) theoretical saturation (samples and encodes data until new categories cease to apply) and (8) memo writing (written register containing the theory development).

Glaser & Strauss (1967) believed that everyone can create their own theory, as long as it is based on real life. They further believed that everyone can be innovative in social research, so-called science entrepreneurs. The theory, however, should be tested and modified.

Grounded theory is a suitable method for studying social processes such as user participation in healthcare services (Foley & Timonen 2015; Charmaz et al. 2018). Grounded theory has been used in many research projects to highlight the experiences of patients with participation, for example, nursing in somatic care (Larsson et al. 2007) for patients with amyotrophic lateral sclerosis (Foley & Timonen 2015), and to highlight the experiences of nurses with patient participation in the health service (Sahlsten et al. 2007).

Data collection in qualitative research on patient participation

Participation can be studied from different points of view, for example from the perspectives of patients, relatives or health professionals. Research shows that patients and health professionals may experience participation in the health service differently (Sahlsten et al. 2007). There are various data collection methods for studying participation when studying the experiences of patients, relatives and health professionals in a patient pathway (Bugge & Jones 2007).

Interviews are often semi-structured or narrative. For semi-structured interviews, an interview guide tends to be used with various themes one wishes to shed light on. The theoretical framework of Thompson and coworkers (2007) can, for example, provide suggestions for themes in an interview guide. In individual interviews, the goal is to collect data that can highlight the complexity of patient participation. Knowledge of patient experiences may provide new insights to use in the development of the health service and in medical guidelines (Røsvik et al. 2010). Several researchers have highlighted the value of a patient and relative perspective. Nurse Elise K. Bårdsgjerde and colleagues (Bårdsgjerde et al. 2019) has conducted interviews with patients to illuminate participation in various phases of acute myocardial infarction. Nurse Anett Skorpen Tarberg and colleagues (Tarberg et al. 2019) have interviewed relatives to illuminate their participation in various phases of palliative care, and nurse and researcher, Elin Aasen and colleagues (Aasen et al. 2012a) has interviewed nurses about the participation of patients in haemodialysis.

Focus groups are often used as a data collection method to illuminate the experiences of health professionals in relation to the participation of patients in healthcare. In order to have rich data, it is recommended to have a homogeneous group - this is because they have a common frame of reference in the discussions (Krueger & Casey 2015). Experience has shown that homogeneous groups are suitable for producing complex experiences and ethical dilemmas in healthcare (Tritter & Landstad 2020). In heterogeneous groups, different positions and different frames of reference may hinder deeper communication of the phenomenon being studied (Tritter & Landstad 2020). Andersen-Hollekim and colleagues (2019) have, for example, conducted focus groups with health professionals to illuminate their experience with patient involvement in different phases of patient pathways with kidney disease.

Observation could be another method for studying participation. Different observation methods are available: participatory, systematic or video recording (Patton 2015). There are some ethical dilemmas associated with observation of patients, and these must be carefully considered before using the method. For example, the observed patient may find it stressful to have a researcher present in a treatment situation. Norwegian nurse and researcher, Ellen Kristvik (2011), carried out fieldwork at a Norwegian hospital. With the aid of observation, she studied the decision-making process in healthcare to find out whose interests were taken care in cancer treatment. She asks critical questions about how informed consent in treatment choices is maintained in clinical practice. She especially highlights the sociocultural context as significant to participation.

*Document and text analys*is is a method that can be used to provide insight into how health professionals communicate with patients and rela-

Qualitative design	Purpose	Data collection methods	Analysis	Study object
Narrative	To create meaning in the story	Narrative interviews	Narrative analysis	Patients, relatives, health professionals
		Documents/texts (letters, diaries)	Narrative analysis with elements of image analysis	
		Visual expressions (photographs, drawings/paints)		
Social constructivism	To understand how different factors affect how participation is expressed	Individual interviews Focus group interviews Observations Documents/texts Websites Visual expressions (pictures)	Social constructivist analysis - meaning is created in social interaction	Patients, relatives, health professionals, health policy processes
Critical discourse analysis	To analyse underlying power structures in communication	Individual interviews Focus group interviews Observations Documents/texts Websites	Analysis at three levels: Text Discursive practice Social context	Patients, relatives, health professionals, health policy processes
Hermeneutics	To interpret texts on participation in historical and cultural contexts	Individual interviews Focus group interviews Observations Documents/texts Websites	Hermeneutic interpretation of text	Patients, relatives, health professionals, health policy processes
Phenomenology	To describe subjective experiences with participation	Individual interviews	Phenomenological analysis of experiences	Patients, relatives, health professionals
Grounded theory	To develop alternative theories based on the context in which the phenomenon has arisen	A fundamental principle is that 'all is data' - for example: Individual interviews Focus group interviews Observations Documents/texts (letters, speeches, memoirs, novels, biographies, newspaper articles) Visual expressions (photographs, films) Websites	The analysis is based on observations rather than using analytical constructs, categories or variables from already proposed or established theories	Patients, relatives, health professionals, health policy processes

tives (Bratberg 2017). Table 1 gives examples of documents and texts relevant to analysis. A number of information leaflets have been designed intended to ensure patient involvement and participation in treatment (Gulbrandsen et al. 2010).

It is important to study participation in mental illness, as this patient group is particularly vulnerable. Norwegian sociologist and researcher Marianne Hedlund and colleagues (2019) have performed document/text analyses on articles, interviews, reports, public documents and websites to study how people with mental health problems can access healthcare through participation in self-help groups. The study adds a critical perspective on how the public health sector can waive responsibility for this patient group.

Photovoice is a method that can be used to document and reflect the needs of different groups to add knowledge that is intended to create change (Wang & Burris 1997). The method means that the participants are given the task of documenting their situation with the help of visual narratives. Photovoice can reveal how patients experience participation in treatment. For example, researchers have used photovoice as a tool to study the experiences of HIV patients with medication for mental reactions to the disease (Werremeyer et al. 2017). Photovoice has also been used in a study on participation in dialysis treatment (Allen & Hutchinson, 2009), and in another study on perceived limitations in relation to wheelchair use (Berland 2007). In these studies, the method has revealed shortcomings in participation in patient treatment.

Table 1: Main features of various qualitative designs. An overview is given of methods that have been used in qualitative research to illuminate patient participation in the health service. Relevant analyses and data collection methods related to various designs are discussed. The last section presents which study object the various designs can illuminate.

Literature

Aasen EM, Kvangarsnes M, Heggen K. (2012a) Nurses' perceptions of patient participation in hemodialysis treatment. Nursing ethics 19: 419–30.

Aasen EM, Kvangarsnes M, Heggen K. (2012b) Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. Scandinavian journal of caring sciences 26: 61–9.

Aasen EM, Kvangarsnes M, Wold B et al. (2012c) The next of kin of older people undergoing haemodialysis: a discursive perspective on perceptions of participation. Journal of Advanced Nursing 68: 1716–25.

Allen D and Hutchinson T. (2009) Using PAR or Abusing its Good Name? the Challenges and Surprises of Photovoice and Film in a Study of Chronic Illness. International Journal of Qualitative Methods 8: 115–28.

Alvesson M, Sköldberg K. (2009) Reflexive methodology : new vistas for qualitative research, London: Sage.

Andersen-Hollekim TE, Kvangarsnes M, Landstad BJ et al. (2019) Patient participation in the clinical pathway—Nurses' perceptions of adults' involvement in haemodialysis. Nursing open 6: 574–82.

Arnstein SPR. (1969) A Ladder Of Citizen Participation. Journal of the American Institute of Planners 35: 216–24.

Berger PL and Luckmann T. (2000) The social construction of reality : a treatise in the sociology of knowledge: Anchor Books.

Berland G. (2007) The View from the Other Side — Patients, Doctors, and the Power of a Camera. The New England Journal of Medicine 357: 2533–6.

Bratberg Ø. (2017) Tekstanalyse for samfunnsvitere, Oslo: Cappelen Damm akademisk.

Brinkmann S and Kvale S. (2015) InterViews : learning the craft of qualitative research interviewing, Thousand Oaks, Calif: Sage.

Bryant A and Charmaz K. (2007) The SAGE handbook of grounded theory, Los Angeles, Calif: Sage.

Bugge C and Jones A. (2007) Methods for studying patient participation. In: Collins S, Britten N, Ruusuvuori J et al. (eds.) Patient Participation in Health Care Consultations Qualitative Perspectives Maidenhead: Open University Press 176–93.

Bårdsgjerde EK, Kvangarsnes M, Landstad B et al. (2019) Patient's narratives of their patient participation in the myocardial infarction pathway. Journal of Advanced Nursing.

Cahill J. (1996) Patient participation: a concept analysis. Journal of Advanced Nursing 24: 561–71.

Castro EM, Van Regenmortel T, Vanhaecht K et al. (2016) Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. Patient education and counseling 99: 1923–39.

Charmaz K, Thornberg R, Keane E. (2018) Evolving Grounded Theory and Social Justice Inquiry. In: Denzin NK and Lincoln YS (eds.) The Sage handbook of qualitative research. 5 ed. Los Angeles, Calif: Sage.

Chase SE. (2018) Narrative Inquiry Toward Theoretical and Methodological Maturity. In: Denzin NK and Lincoln YS (eds.) The Sage handbook of qualitative research. 5 ed. Los Angeles, Calif: Sage.

Clandinin DJ, Connelly FM. (2000) Narrative inquiry: Experience and story in qualitative research, San Francisco: Jossey-Bass.

Creswell JW, Creswell JD. (2018) Research design: qualitative, quantitative & mixed methods approaches, Los Angeles, California: Sage.

Crossley N. (1996) Intersubjectivity: The Fabric of Social Becoming, London: United Kingdom, London: SAGE Publications.

Fairclough N. (1992) Discourse and social change, Cambridge: Polity Press.

Fairclough N. (2001) Language and power, Harlow: Longman.

Foley G, Timonen V. (2015) Using Grounded Theory Method to Capture and Analyze Health Care Experiences. Health Services Research 50: 1195–210.

Foss C, Kirkevold M. (2008) Unfolding the invisible of the visible: gendered constructions of patient participation. Nursing Inquiry 15: 299–308.

Gadamer H. (1999) Forståelens historicitet som hermeneutisk princip. In: Gulddal J and Møller M (eds.) Hermeneutik: en antologi om forståelse. København: Gyldendal.

Gilje N. (2019) Hermeneutikk som metode : ein historisk introduksjon, Oslo: Samlaget.

Gjengedal E. (1994) Understanding a world of critical illness: a phenomenological study of the experiences of respirator patients and their caregivers. Bergen: Department of Public Health and Primary Health Care, Division for Nursing Science, University of Bergen.

Glaser BG, Strauss AL. (1967) The discovery of grounded theory : strategies for qualitative research, New York: Aldine de Gruyter.

Gulbrandsen P, Førde R, Kristvik E. (2010) Informasjonsskriv før inngrep. Tidsskrift for Den norske legeforening 130: 1705.

Gulddal J, Møller M. (1999) Hermeneutik : en antologi om forståelse, København: Gyldendal.

Habermas J. (1999) Kraften i de bedre argumenter [The power of better arguments], Oslo: Ad notam Gyldendal.

Hedlund M, Landstad BJ,Tritter JQ. (2019) The disciplining of self-help: Doing self-help the Norwegian way. Social science & medicine 225: 34–41.

Helse- og omsorgsdepartementet. (2009a) Nasjonal helseplan (2007–2010). https://www.regjeringen.no/globalassets/upload/hod/sykehus/nasjonal_helseplan_sartrykk.pdf.

Helse- og omsorgsdepartementet. (2009b) Samhandlingsreformen: rett behandling – på rett sted – til rett tid. Oslo: Helse- og omsorgsdepartementet.

Holloway I, Freshwater H. (2007) Narrative Research in Nursing, Oxford, UK: Blackwell

Howell KE. (2013) An introduction to the philosophy of methodology, Los Angeles: SAGE.

Husserl E. (1965) Philosophy as Rigorous Science. In: Husserl E (ed.) Phenomenology and the Crisis of Philosophy. Philosophy as Rigorous Science and Philosophy and the Crisis of European Man. New York: Harper & Row.

Jones F, Rodger S, Ziviani J et al. (2012) Application of a hermeneutic phenomenologically orientated approach to a qualitative study. International Journal of Therapy and Rehabilitation 19: 370–8.

Kristvik E. (2011) For whom and for what? Exploring the question of'informed consent in treatment decision making processes. Medische Antropologie 23: 29–43.

Krueger RA and Casey MA. (2015) Focus groups : a practical guide for applied research, Los Angeles: Sage.

Kvangarsnes M, Torheim H, Hole T et al. (2013a) Intensive care unit nurses' perceptions of patient participation in the acute phase of chronic obstructive pulmonary disease exacerbation: an interview study. Journal of Advanced Nursing 69: 425–34.

Kvangarsnes M, Torheim H, Hole T et al. (2013b) Narratives of breathlessness in chronic obstructive pulmonary disease. Journal of clinical nursing 22: 3062–70.

Larsson IE, Sahlsten MJ, Sjöström B et al. (2007) Patient participation in nursing care from a patient perspective: a Grounded Theory study. Scandinavian journal of caring sciences 21: 313–20.

Marquard O. (1999) Spørgsmålet om det spørgsmål, som hermeneutikken er svar på.

I: Gulddal J, Møller M red. Hermeneutik: en antologi om forståelse. København: Gyldendal.

Martinsen K, Eriksson K. (2003) Fenomenologi og omsorg : tre dialoger, Oslo: Universitetsforlaget.

Mead GH, Morris CW, Huebner DR et al. (2015) Mind, self, and society, Chicago,London: University of Chicago Press.

Morse JM, Stern PN, Corbin JM et al. (2009) Developing grounded theory: the second generation, Walnut Creek, Calif: Left Coast Press.

Patton MQ. (2015) Qualitative research & evaluation methods : integrating theory and practice, Los Angeles, Calif: Sage.

Rise MB, Steinsbekk A, Grimstad H et al. (2012) Lifting the veil from user participation in clinical work – What is it and does it work? : Norwegian University of Science and Technology.

Røsvik AH, Movik E, Nylenna M. (2010) Deltar pasientene i utviklingen av kliniske retningslinjer i Norge? Tidsskrift for den Norske Laegeforening 130: 2236–8.

Sahlsten MJ, Larsson IE, Sjöström B et al. (2007) Patient participation in nursing care: towards a concept clarification from a nurse perspective. Journal of clinical nursing 16: 630–7.

Sahlsten MJ, Larsson IE, Sjöström B et al. (2008) An analysis of the concept of patient participation. Nursing forum. Wiley Online Library, 2–11.

Språkrådet. Narrativ. https://www.sprakradet.no/svardatabase/sporsmal-og-svar/narrativ-bruk-og-genus/.

Starrin B. (1996) Grounded Theory – En modell för kvalitativ analys. In: Starrin B and Svensson P-G (eds) Kvalitativa studier i teori och praktik. Lund: Studentlitteratur.

Starrin B and Svensson P-G. (1996) Kvalitativa studier i teori och praktik, Lund: Studentlitteratur.

Store norske leksikon. Sosialkonstruktivisme. https://snl.no/sosialkonstruktivisme.

Tarberg AS, Kvangarsnes M, Hole T et al. (2019) Silent voices: Family caregivers' narratives of involvement in palliative care. Nursing open 6: 1446–54.

Thomas C. (2010) Negotiating the contested terrain of narrative methods in illness contexts. Sociology of Health & Illness 32: 647–60.

Thompson A. (2007) The meaning of patient involvement and participation in health care consultations: a taxonomy. Social science & medicine 64: 1297–310.

Thompson A, Ruusuvuori J, Britten N et al. (2007) An integrative approach to patient participation in consultations In: Collins S, Britten N, Ruusuvuori J, et al. (eds) Patient Participation in Health Care Consultations Qualitative Perspectives Maidenhead: Open University Press 176–93.

Torheim H, Kvangarsnes M. (2014) How do patients with exacerbated chronic obstructive pulmonary disease experience care in the intensive care unit? Scandinavian journal of caring sciences 28: 741–48.

Tritter J, Landstad B. (2020) Focus Groups. In: Mays N and Pope C (eds.) Qualitative Research in Health Care 4ed. Malden, Mass: Blackwell BMJ Books, 57–66.

Wang C, Burris MA. (1997) Photovoice: Concept, methodology, and use for participatory needs assessment. Health education & behavior 24: 369–87.

Werremeyer A, Skoy E, Aalgaard Kelly G. (2017) Use of Photovoice to Understand the Experience of Taking Psychotropic Medications. Qualitative Health Research 27: 1959–69.

WHO. (2013) Exploring patient participation in reducing health-care-related safety risks. In: Delnoij D, Hafner V (eds.). World Health Organization.

Willig C. (2013) Introducing Qualitative Research In Psychology, Maidenhead: Maidenhead: McGraw-Hill Education.

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