Interactions between women with rheumatoid arthritis and nurses during outpatient consultations

A qualitative study

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Published in:
Musculoskeletal Care

DOI:
10.1002/msc.1435

Publication date:
2019

Document version:
Submitted manuscript

Citation for pulished version (APA):
Feddersen, H., Kristiansen, T. M., Andersen, P. T., Hørslev-Petersen, K., & Primdahl, J. (2019). Interactions between women with rheumatoid arthritis and nurses during outpatient consultations: A qualitative study. *Musculoskeletal Care*, *17*(4), 363-371. https://doi.org/10.1002/msc.1435

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Abstract

Introduction: Rheumatoid arthritis (RA) is a chronic inflammatory disease, and patients with RA receive services in various settings, e.g., in nurse-led follow-up consultations. This study aimed to investigate how the management of RA in everyday life is expressed in interactions between nurses and women with RA during nursing consultations.

Methods: The study was conducted as constructivist grounded theory, with data based on participant observations and subsequent interviews with 10 women with RA.

Results: A core category was developed, "Collaboration through mutual acknowledgement", which documented how the women and nurses confirmed their shared understanding of the content and the structure of the consultation. Three subcategories were identified:

1) "On safe ground", which illustrated that biomedical factors, such as blood test results and pharmacological treatment, structured the basis of the dialogue.

2) "Venturing forward", which documented how both parties were aware of each other's reactions when the dialogue dealt with women's perspectives of illness in their everyday lives.

3) "Gentle steering", which showed that the nurses gently steered the dialogue if the women strayed from the planned content.

Conclusion: Both parties agreed that a disease perspective consistent with biomedical factors formed the basis for further dialogue. Subsequently, the women's perspectives on illness were included, and the women felt acknowledged. Therefore, the recommendation is that the consultations start by agreeing on a shared agenda to facilitate the inclusion of the women's perspectives on illness.

Keywords
Illness; inflammatory arthritis; nurse-led follow-up; constructivist grounded theory; participant observations; qualitative interviews; Goffman

Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory disease characterized by swollen, sore and stiff joints, pain and fatigue (Jeffery, 2014; McInnes & Schett, 2017). Women develop RA approximately three times more often than men (Jeffery, 2014; Scott, Wolfe, & Huizinga, 2010) and generally report more serious symptoms than men (Sokka et al., 2009). The disease can lead to reduced psychological well-being, reduced social participation (Kristiansen, Primdahl, Antoft, & Horslev-Petersen, 2012), increased absence due to sickness (Hansen, 2016; Lenssinck et al., 2013) and permanent withdrawal from the labour market.

Despite symptoms and fluctuating trajectories, women often try to downplay the disease in social interactions with others, i.e., during paid work and motherhood responsibilities (Feddersen, Mechlenborg Kristiansen, Tanggaard Andersen, Horslev-Petersen, & Primdahl, 2018). It is recommended that people with RA be offered outpatient follow-up with an ongoing view to keep disease activity at bay and, thus, improve their quality of life (Smolen et al., 2016).

Several studies show that patients with RA value nursing consultations (Bala et al., 2012; Primdahl, Wagner, Holst, & Horslev-Petersen, 2012). However, there is a lack of knowledge about what actually happens in these interactions between nurses and patients, including how women currently express their understanding of illness management in everyday life. Therefore, the aim of this study was to investigate how management in everyday life with RA is expressed in interactions between nurses and women with RA during nursing consultations.

Method

Design

In this study, the social interaction between the nurses and women was considered to play a crucial role in how the women's understanding of illness in everyday life is expressed. Charmaz' constructivist-grounded theory (CGT) (Charmaz, 2014) was chosen as the method because it is suitable when social interactions and social processes are the subject of study. CGT is inspired by symbolic interactionism, in which people act based on the meanings that things and other people have for them (Blumer, 1969/1986). CGT is an inductive approach, with a starting point in empirical data in order to develop concepts, models or theories. Furthermore, it is stated that the researcher and the participants jointly create the data, which means that both the researchers' and the participants' perspectives shape the data. Data collection and analysis are carried out simultaneously, and constant comparison is pivotal to build up concepts, models or theories in CGT (Charmaz, 2014).

Participants

In connection with an earlier study on women's handling of RA, motherhood and working life (Feddersen et al., 2018), women were included according to the principles of purposeful sampling (Silverman, 2013) and *theoretical sampling* (Charmaz, 2014), which entails continuing to include participants and generate data until robust theoretical categories can be developed (Charmaz, 2014). This goal was achieved after inclusion of 10 participants. The sample size was small in keeping with qualitative research, where the aim is to provide an in-depth exploration of the experience of individuals (Patton 2015). To be eligible, the following criteria had to be fulfilled: diagnosed with RA, involved in the labour market and pregnant or with at least one child living at home. The latter criteria was included because earlier studies have documented that women diagnosed with RA feel challenged in motherhood with responsibilities related to pregnancy and providing caregiving for children in the household (Feddersen et al., 2018; Kristiansen et al., 2012; Meade et al., 2013).

Nurses and physicians at the hospital where the women were outpatients served as gatekeepers to briefly inform potential participants about the purpose of the study and offer further information. The first author informed interested women orally and in writing about the study. Women who wanted to participate gave their oral and written consent. The ten women agreed to participate in the current study. The characteristics of the 10 women included in the present study are shown in Table 1.

This study was carried out in accordance with the Declaration of Helsinki (World Medical Association, 2018), and the Danish Data Protection Agency granted permission to store the data (Journal no.: 13/12552 doc. No. 12, notification umbrella no. 2008-58-0035). The Regional Committee on Health Research Ethics confirmed that, in accordance with Danish legislation, the study did not require formal approval, as no biomedical material was included.

Nursing consultations

Nursing consultations are offered to both newly diagnosed patients and those with stable RA at a Danish rheumatology hospital as part of their outpatient follow-up (Primdahl, Sorensen, Horn, Petersen, & Horslev-Petersen, 2014). Intervals between consultations vary according to patients' needs. Newly diagnosed patients alternately see a rheumatologist and a nurse. The nursing consultations include an assessment of blood test responses, a joint examination and an up-to date summary of the pharmacological treatment. A local guideline stipulates that the patient's current issues, goals and expectations must be included and that the nurses are responsible for prioritizing time and resources in connection with the consultations. In addition, it is stated that the patient's

assessment of the rheumatic activity must be included and that issues relating to everyday life can be included in the dialogue (unpublished local guideline).

Data generation

Data were generated on the basis of participant observations (Hammersley & Atkinson, 2007; Knoblauch, 2005) during nursing consultations.

The consultations lasted between 15 and 45 minutes. The average duration of the consultations was 20 minutes.

The participant observations started when the researcher (first author) met the women in the waiting room before the nursing consultations and continued until the women left the hospital. During the consultations, the researcher observed the consultations and aimed to balance between not interrupting the dialogue between the women and the nurses while at the same time sitting close enough to be able to observe their faces during the interactions. The purpose of participant observation was more to observe than to participate (Hammersley and Atkinson, 2007). The researcher took brief notes during the consultations, and shortly after the consultations, the jottings were re-written to more detailed field notes (Emerson, Fretz, Shaw, 2011).

The participant observations were followed by individual, qualitative interviews (Charmaz, 2014). The development of the interview guides was informed by the field notes from the observations. The first author made a draft of the interview guide, and, after discussing it with the co-authors, the interview guide was finalised. All of the interviews started with open and broad questions regarding the participants' experiences with the current consultation followed by more individual and focused questions concerning what the researcher actually had observed during the consultation. An example of an interview guide is shown in Table 2.

The data collection and most of the analysis were carried out before the two patient research partners were involved. They did not participate in the data collection or in the development of the interview guide.

The first author conducted the face-to-face interviews in a suitable room at the hospital, in the participants' homes or on the telephone, in accordance with participants' wishes. The interviews lasted between 25 and 90 minutes; the average time was 35 minutes. The interviews were digitally recorded and subsequently transcribed verbatim (Charmaz, 2014).

Data analysis

Data generation and analysis took place as two parallel processes and continued with an increasing focus throughout the data generation (Charmaz, 2014).

Three phases of coding of the transcribed interviews and field notes were conducted: initial, focused and theoretical (Charmaz, 2014). The initial and focused coding were carried out as an inductive process focusing on the participants' perspectives. In the final theoretical coding, the analysis was developed in light of a more general and, thus, abstract understanding. For that purpose, external ideas and concepts were drawn upon as inspiration for the construction of preliminary categories (Charmaz, 2014). Goffman's (Goffman, 2005) concept of "face-work", relating to social interactions in a specific face-to-face situation, was used based on the empirical data and study aim. The robustness of the preliminarily developed categories was tested by returning to the empirical data to explore whether these preliminary categories were supported by the data (Charmaz, 2014). All authors contributed to the analysis.

Goffman's face-work as a theoretical framework of interpretation

Goffman describes the social interaction in any given face-to-face meeting as an interaction in which the parties strive to make the meeting go as smoothly as possible so that neither party loses dignity or reputation. The encounter is fragile due to the risk of collapse. Through a pattern of verbal and non-verbal actions, the parties show their perception of the situation; i.e., they practise a so-called *line*. The parties' self-images are presented through the concept of *face*. A person is emotionally affected by the way in which the presentation of the face is accommodated in the interaction. When it is possible to live up to one's own and others' expectations of how to act in the social encounter, i.e. the face appears in accordance with or in a more favourable light than expected, then the experience is positive. However, the experience can be one of embarrassment and shame if it is not possible to live up to one's own and others' expectations of how to act in the social encounter, i.e. in situations where one might lose face (Goffman, 2005).

By applying ritual principles, i.e., *remedial interchanges*, the parties try to prevent anyone from losing face in the social encounter, for example, by showing respect and tactfully turning a blind eye. The corrective process is an example of a remedial interchange. This approach can be applied if one of the parties does not act as expected. In such a case, the other party can make this discrepancy visible by pointing out the occurrence. The person who acted in the unexpected way thus has the opportunity to correct it and can re-establish the situation to avoid a collapse in the encounter (Goffman, 2005).

Results

Based on the analysis, one core category *Collaboration through mutual acknowledgement* and three subcategories 1) *On safe ground*, 2) *Venturing forward* and 3) *Gentle steering* were developed.

Collaboration through mutual acknowledgement

Collaboration through mutual acknowledgement describes the overall social process in nursing consultations, in which both the women and the nurses, through verbal and nonverbal communication (Goffman, 2005), collaborated on a shared way of defining and thus acting upon the situation. The consultations followed a similar structure in terms of content, duration and pattern and can therefore be characterized as having a ritual character. In the collaboration, both parties strived to avoid offending the other person, i.e., their respective positive self-images (Goffman, 2005), thereby avoiding a collapse of the consultation.

On safe ground

A general feature was that the women and nurses collaborated on a definition of the nursing consultation, within which the disease's biomedical aspects, i.e., blood tests, examination of the joints and discussion of the pharmacological treatment, formed the basis of the dialogue. Neither the nurses nor the women showed any signs of uncertainty as to whether these aspects were significant, pivotal points in the dialogue. Thus, without hesitation, they respected each other's *faces* and *lines* (Goffman, 2005). An example of this finding is that the nursing consultations usually started with the nurses reviewing the blood test results that had been taken ahead of the nursing consultations. The nurse and woman would sit at two adjoining sides of a desk. The nurse would show the blood test results by turning the computer screen towards the woman so they could both see the screen, while the nurse pointed to the relevant results. The nurse observed the woman, apparently to see her reactions.

This procedure took place at all consultations observed. The nurses continued to explain and elaborate on the importance of the numbers, which would be the starting point of the dialogue, and some women asked for further explanation. If the blood tests, for example, showed abnormal values, the woman could offer her own possible explanations for this by, e.g., stating that she had a

cold at that moment. The nurses showed an interest in the women's explanations by maintaining eye contact and by actively engaging in discussions. It worked as a smooth collaboration where the two parties, by observing each other, mutually confirmed the nature of the consultation. The nurses were accepted as experts in the biomedical field, while the women's role was that of patients who would like to receive information, advice and guidance. It was primarily on the nurse's initiative that the blood test results and pharmacological treatment were discussed and that examination of the joints was initiated. Thus, the nurses assumed the main responsibility for the fact that the biomedical aspects of the disease were included in the nursing consultations. Additionally, the nurses showed that they were open to the women's wishes and need to get more detailed explanations by asking if they had understood the information or if they wanted further explanation. This motivated the women to ask specific questions and thereby actively participate in the dialogue.

The field note below illustrates this:

> *The participant says that she has side effects of the medication in the form of stomach problems … The nurse says "maximum doses of several medications may be needed". First, the participant listens while maintaining eye contact with the nurse. Then, the nurse moves closer to the woman and takes the medical record nearer to her. This causes the woman to bend forward and look in the record. She then nods and answers the nurse: "It might be a good idea." The nurse looks at the woman and says "Might? What do you mean? It's the side effects that are bad and worrying you?" The woman nods, and she elaborates on her description of the side effects* (Field note, participant I).

The nurses' knowledge about the biomedical aspects of the disease was included in their interaction, and the women participated by allowing the nurses to examine their joints. Both parties showed respect for each other, and neither of them compromised or lost face in this interaction. There was a congruence between the *lines* practised by the nurses and the women and their *faces*.

The ritual nature of the interactions was seen in the tacit consensus about what was going to happen. The following field note illustrates this:

> *The nurse turns to the woman, leans over the table with out-stretched and upward-facing palms. This causes the woman to lay her hands in the nurse's hands, and the nurse begins to examine the woman's finger joints. This takes place without words but is initiated by eye contact between the two, and the gaze of both is then directed towards the hands* (Field note, participant J).

In the subsequent interviews, the women expressed that they valued the nurses' biomedical knowledge. For example, one woman needed to discuss her concerns about side effects in relation to switching to another pharmacological treatment. In the interview that followed her consultation, she said:

> *I think she [the nurse] responded very factually, and I also believed her because she could explain that it [the pharmacological medication] had been monitored and its side effects investigated and all that for 25 years. So, it is not as new as one can imagine at first. (…) The nurses are actually, like, more receptive to hearing about one's own experiences … they are skilled nurses, they listen to what one says and take it seriously and respond properly to one's questions* (Interview, participant E).

Venturing forward

When the women's own understanding of everyday life with the disease was included in the nursing consultations, this did not happen in the same way as when the biomedical aspects of the disease were discussed. The interactions involving everyday life could be characterized as involving

particularly sensitive facial work. The nurses' social skills, such as being good at perceiving what the other person was expressing and utilizing tact, conduct and diplomacy were basic factors required for the dialogue to succeed without collapse (Goffman, 2005). The following field note illustrates how both parties performed facial work with mutual respect so as not to compromise each other's faces:

> *The nurse looks at the computer screen and says she is happy with the blood test results and that it looks good, but she adds that she should "just" ask the woman how it's going. The participant shrugs her shoulders and answers: "It's going". The nurse looks at the woman and asks, "How should I interpret that?" The woman says that she has been on a work trial and that she can't work because of problems with her hands. The nurse asks for more information about the work trial, and the woman elaborates further. This leads to them discussing the challenges that are specific to the work trial* (Field note, participant C).

The field note illustrates that the nurse took the initiative to allow the woman's perception of the disease and its implications for her working life to be included in the dialogue, and the woman accepted the invitation.

The initiative to bring the women's perceptions of the disease into the dialogue could also take place at the women's request, and the nurses respected this. Both parties' *lines* showed that they ventured cautiously when they offered each other mutual attention and that they respected each other's lines in an attempt to preserve each other's faces.

> *The nurse checked the woman's joints while observing the woman's face. The woman made a grimace and let out a low sound, and the nurse removed her hands from the joint.*

The woman looked at the nurse and said she thought that the swelling was due to lifting her child and that it could therefore be muscle pain and not joint pain. The nurse responded – while observing the woman – that the results of the blood tests indicated that the soreness could be due to increased disease activity. She suggested an injection into the joint. The woman stated that she did not want the injection because she experienced that she could not sleep when she was given injections. The nurse said: "I support your decision" (Field note, participant B).

The majority of the women stated that they felt acknowledged and respected by the nurses, including cases where the nurses suggested treatment that the women did not accept, as described in the field note above.

One of the women, however, reported that, in the past, she had felt uncomfortable because the nurse did not trust her when she told her about her pain. However, in relation to the current consultation, she felt that she had been taken seriously.

Gentle steering

Some of the women expressed the wish to reduce their medication and, in relation to this, discussed possible risks of not being able to continue participating in their working lives to the extent they had before. However, the following participant observation is seen as an example of how the nurses set limits as to how much time was taken up by the discussion of working life.

A woman says she has increased her number of weekly working hours because she is getting on well with her current medicine. The nurse says she can understand this well and that it is nice "to feel that one is needed". The woman nods and continues to elaborate on this but is interrupted by the nurse who says with a little smile: "So, back

to the rheumatism" as a request to continue the consultation with a joint examination. The woman stops talking (Field note, participant G).

In the interview that followed the consultation, the woman related that she felt engaged with and taken seriously by the nurse. The example also illustrates how the faces were presented and how a potential threat of breakdown in the meeting could be seen when the nurse interrupted the woman. A repair ritual [18] prevented any breakdown, where the woman accepted the interruption by politely following the nurse's instructions.

Discussion

The results show that the consultations contained two different perspectives: the biomedical aspects of the disease and the women's understanding of living with the disease in everyday life.

The two different perspectives are representative of a distinction between illness and disease. The biomedical factors relate to the disease perspective, while the women's understanding, including the mental and social aspects, relate to the illness perspective (Conrad & Barker, 2010; Kleinman & Becker, 1998).

This study documents that the disease perspective forms the basis for further dialogue and that both parties agree on this priority through the ritual nature of the consultations. Several studies have shown that biomedical factors, i.e., the disease perspective, are prioritized at the expense of how patients understand and live with their illness, i.e., the illness perspective (Kang & Stenfors-Hayes, 2016; Maten-Speksnijder, Dwarswaard, Meurs, & Staa, 2016; McCormack, Karlsson, Dewing, & Lerdal, 2010; Zoffmann, Harder, & Kirkevold, 2008).

This study shows that the illness perspective is included; however, both nurses and women engage with it reluctantly. One explanation as to why this study deviates from the above research could be

that cultural differences are seen across countries in relation to the weighting of illness and disease perspectives (Meuweesen et al., 2009).

In addition, an explanation for the varying practices could be attributed to the fact that there is no equivalency between guidelines regarding the role and responsibility of the nurses between countries nor within individual countries (Martínez-González et al., 2014; van Eijk-Hustings et al., 2012). The nurses in this study work according to a local guideline, which states that the patients' current issues, goals and expectations must be considered. This approach could be a contributory factor for the implementation of a person-centred approach, in which nurses would include the women's illness perspective (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). Furthermore, the content of medical consultations could have been be transferred to the nursing consultations, either intentionally or unintentionally. This transfer could be a contributory factor in the prioritization of the disease perspective in the abovementioned studies and could be a reason why the nurses take this perspective as the starting point, as also seen in the current study. In many countries, nursing consultations have been introduced as an alternative to medical consultations, with the same level and standard of disease control as provided for patients who receive only medical consultations (de Thurah, Esbensen, Roelsgaard, Frandsen, & Primdahl, 2017; Martínez-González et al., 2014; Primdahl et al., 2014; Rudan et al., 2015). In light of this, consideration should be given as to who defines the nurse's role in the nursing consultations. It could be the case that the nurse's role in the nursing consultation may be described as a task transfer and thus a substitute for a medical consultation. Conversely, it could be that the nurses have been trained to independently undertake joint examinations and assess the medication side effects as a supplementary aspect of their nursing care and support of patients (Bala et al., 2012; Primdahl, Wagner, & Horslev-Petersen, 2011).

The ritual nature of the consultations can be seen in light of both parties' actions. The nurses' training, their professional experiences and compliance with a local guideline may have informed their actions. The women's actions may have been shaped by their experiences in previous consultations or by other meetings with health professionals.

The findings from this study can also illustrate the gap between task-centred and person-centred nursing (Kitson & Soerensen, 2017). In task-centred nursing, the focus is on increased specialization, leading to the risk of nursing being reduced to technically instrumental nursing. Person-centred nursing is based on the relationship between the nurse and the patient, which is regarded as a prerequisite for the nurses' empathy and understanding of the patient's situation. It is claimed that task-centred nursing is currently gaining ground and is displacing the person-centred approach (Kitson & Soerensen, 2017). When the task-centred approach becomes dominant, there is a risk that nursing will be fragmented into tasks that are detached from what the individual patient needs, thereby negatively affecting the quality of nursing (Kitson & Soerensen, 2017). The women appreciated the biomedical knowledge held by the nurses. Although the biomedical aspects formed the basis of the consultations, the nurses' understanding of the women's perspectives was crucial to the women's sense of being acknowledged. This study can thus illustrate that, when nursing care "crosses the caring chasm" between task-centred and person-centred nursing (Kitson & Soerensen, 2017), women feel that the nursing consultations are valuable.

This study shows that health-related decisions in the consultations are made both on the basis of the women's understanding of how they live with the illness and the nurses' biomedical perspective. This means that the way nurses and women work together is based on the principles of the concept

of shared decision making (SDM), which is characterized by health professionals contributing their expertise about the disease and patients contributing their experiences of living with the illness, with a view towards making health-related decisions together (Coulter & Collins, 2011; Elwyn et al., 2017; Lewis, Stacey, Squires, & Carroll, 2016).

Similar principles of including both patients' and health professionals' perspectives apply in the Calgary-Cambridge model (Burt et al., 2014; Kurtz, Silverman, Benson, & Draper, 2003; Main, Buchbinder, Porcheret, & Foster, 2010). This model, however, also includes considerations about the organization and structure of the dialogue between health professionals and patients, in which a common agenda is first agreed upon. One way to create a more secure basis for involving women's understanding is to agree on a common agenda for the consultation at the very beginning of the consultations, as in the Calgary-Cambridge model.

It is seen as a strength that data were generated based on diverse data (Salmon & Young, 2018), i.e., both participant observations and interviews. Thus, the specifics of the interactions in the participant observations were noticed and described, and in the subsequent interviews, it was possible to ask questions about the women's experiences of the specific interactions.

Data from both participant observations and interviews with 10 women yielded complete saturation of the data (Finset, 2008).

Using Goffman's concept as a theoretical framework to achieve analytical generalization (Polit & Beck, 2010) strengthened the analysis of the data.

Feedback on the findings from two patient research partners showed that their experiences were in line with findings in this study, which adds validity to the interpretations.

A weakness of this study is that data came from nursing consultations within a single hospital, meaning that any nuances and differences in how interactions take place could not be detected. It may be significant to the findings that the first author is a woman and a nurse and was a Ph.D.

student in the hospital where the data were generated. These facts could have caused the women to speak more positively about the nursing consultations than they would have otherwise.

Conclusion

The study shows that both the nurses and women worked together to define the situation so that the disease's biomedical aspects (disease perspective) were fundamental to the subsequent discussion of the women's illness management in everyday life. The interactions took place free of conflict, and when they were related to the disease perspective, they were regarded as having a ritual character.

The women appreciated their experiences and felt acknowledged when the nurses took their perceptions seriously (illness perspective). The interactions linked to the illness perspective took place with mutual caution. The inclusion of the women's experiences of the disease in the dialogue along with the nurse's biomedical knowledge could be an illustration that a bridge had been built between person-centred and task-centred nursing and that the interactions in nursing consultations proceeded according to the principles of SDM.

To overcome the uncertainty that both nurses and women showed when the illness perspective was brought into the dialogue, the recommendation is that the opportunity to include the illness perspective (if the patient wishes) be clearly legitimized by starting the consultation by agreeing to a shared agenda.

References

Bala, S. V., Samuelson, K., Hagell, P., Svensson, B., Fridlund, B., & Hesselgard, K. (2012). The experience of care at nurse-led rheumatology clinics. *Musculoskeletal Care, 10*(4), 202-211. doi:10.1002/msc.1021

Blumer, H. (1969/1986) Symbolic Interactionism: Perspectives and Method, CA, University of California Press.

Burt, J., Abel, G., Elmore, N., Campbell, J., Roland, M., Benson, J., & Silverman, J. (2014). Assessing communication quality of consultations in primary care: initial reliability of the Global Consultation Rating Scale, based on the Calgary-Cambridge Guide to the Medical Interview. *BMJ Open, 4*(3), e004339. doi:10.1136/bmjopen-2013-004339

Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Educ Couns, 99*(12), 1923-1939. doi:10.1016/j.pec.2016.07.026

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). Los Angeles: Sage.

Conrad, P., & Barker, K. K. (2010). The social construction of illness: key insights and policy implications. *Journal of Health and Social Behavior, 51 Suppl*, S67-79. doi:10.1177/0022146510383495

Coulter, A., & Collins, A. (2011). *Making shared decision making a reality: no decision about me without me*. Retrieved from London:

de Thurah, A., Esbensen, B. A., Roelsgaard, I. K., Frandsen, T. F., & Primdahl, J. (2017). Efficacy of embedded nurse-led versus conventional physician-led follow-up in rheumatoid arthritis: a systematic review and meta-analysis. *RMD Open, 3*(2), e000481. doi:10.1136/rmdopen-2017-000481

Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., . . . Van der Weijden, T. (2017). A three-talk model for shared decision making: multistage consultation process. *Bmj, 359*, j4891. doi:10.1136/bmj.j4891

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). Writing ethnographic fieldnotes. University of Chicago Press.

Feddersen, H., Mechlenborg Kristiansen, T., Tanggaard Andersen, P., Horslev-Petersen, K., & Primdahl, J. (2018). Juggling identities of rheumatoid arthritis, motherhood and paid work - a grounded theory study. *Disabil Rehabil*, 1-9. doi:10.1080/09638288.2018.1433723

Finset, A. (2008). Qualitative methods in communication and patient education research. *Patient Educ Couns, 73*(1), 1-2. doi:10.1016/j.pec.2008.08.004

Goffman, E. (2005). On Face-Work *Interaction ritual : essays in face-to-face behavior* (New edition ed., pp. p. 5-46). New Brunswick, N.J.: AldineTransaction.

Hammersley, M., & Atkinson, P. (2007). *Ethnography. Principles in practice* (Third edition ed.). New York: Routledge.

Hansen, S. M. (2016). *Rheumatoid Arthritis and Work.* (PhD PhD. Thesis), University of Copenhagen.

Jeffery, R. C. (2014). Clinical features of rheumatoid arthritis. *Medicine (United Kingdom), 42*(5), 231-236.

Kang, H., & Stenfors-Hayes, T. (2016). Feeling Well and Having Good Numbers: Renal Patients' Encounter With Clinical Uncertainties and the Responsibility to "Live Well". *Qualitative Health Research, 26*(12), 1591-1602.

Kitson, A., & Soerensen, E. E. (2017). Editorial: Crossing the caring chasm. *J Clin Nurs, 26*(13-14), 1753-1756. doi:10.1111/jocn.13619

Kleinman, A., & Becker, A. E. (1998). "Sociosomatics": the contributions of anthropology to psychosomatic medicine. *Psychosomatic Medicine, 60*(4), 389-393.

Knoblauch, H. (2005). *Focused ethnography.* Paper presented at the Forum Qualitative Sozialforschung/Forum: Qualitative Social Research.

Kristiansen, T. M., Primdahl, J., Antoft, R., & Horslev-Petersen, K. (2012). It means everything: continuing normality of everyday life for people with rheumatoid arthritis in early remission. *Musculoskeletal Care, 10*(3), 162-170. doi:10.1002/msc.1013

Kurtz, S., Silverman, J., Benson, J., & Draper, J. (2003). Marrying content and process in clinical method teaching: enhancing the Calgary-Cambridge guides. *Academic Medicine, 78*(8), 802-809.

Lenssinck, M. L., Burdorf, A., Boonen, A., Gignac, M. A., Hazes, J. M., & Luime, J. J. (2013). Consequences of inflammatory arthritis for workplace productivity loss and sick leave: a systematic review. *Ann Rheum Dis, 72*(4), 493-505. doi:10.1136/annrheumdis-2012-201998

Lewis, K. B., Stacey, D., Squires, J. E., & Carroll, S. (2016). Shared Decision-Making Models Acknowledging an Interprofessional Approach: A Theory Analysis to Inform Nursing Practice. *Research and Theory for Nursing Practice, 30*(1), 26-43.

Main, C. J., Buchbinder, R., Porcheret, M., & Foster, N. (2010). Addressing patient beliefs and expectations in the consultation. *Best Practice & Research Clinical Rheumatology, 24*(2), 219-225.

Martínez-González, N. A., Djalali, S., Tandjung, R., Huber-Geismann, F., Markun, S., Wensing, M., & Rosemann, T. (2014). Substitution of physicians by nurses in primary care: a systematic review and meta-analysis. *BMC Health Services Research, 14*(1), 214.

Maten-Speksnijder, A. J., Dwarswaard, J., Meurs, P. L., & Staa, A. (2016). Rhetoric or reality? What nurse practitioners do to provide self-management support in outpatient clinics: an ethnographic study. *Journal of Clinical Nursing, 25*(21-22), 3219-3228.

McCormack, B., Karlsson, B., Dewing, J., & Lerdal, A. (2010). Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scandinavian Journal of Caring Sciences, 24*(3), 620-634.

McInnes, I. B., & Schett, G. (2017). Pathogenetic insights from the treatment of rheumatoid arthritis. *Lancet, 389*(10086), 2328-2337. doi:10.1016/s0140-6736(17)31472-1

Meade, T., Sharpe, L., Hallab, L. et al. (2013) Navigating motherhood choices in the context of rheumatoid arthritis: women's stories. Musculoskelet Care.11:73–82.

Patton, M. Q. (2015) Qualitative research & evaluation methods. (4th. edition) Los Angeles: Sage.

Polit DF, Beck CT. (2010) Generalization in quantitative and qualitative research: myths and strategies. Int J Nurs Stud. 47:1451–1458

Primdahl, J., Sorensen, J., Horn, H. C., Petersen, R., & Horslev-Petersen, K. (2014). Shared care or nursing consultations as an alternative to rheumatologist follow-up for rheumatoid arthritis outpatients with low disease activity--patient outcomes from a 2-year, randomised controlled trial. *Ann Rheum Dis, 73*(2), 357-364. doi:10.1136/annrheumdis-2012-202695

Primdahl, J., Wagner, L., Holst, R., & Horslev-Petersen, K. (2012). The impact on self-efficacy of different types of follow-up care and disease status in patients with rheumatoid arthritis--a randomized trial. *Patient Educ Couns, 88*(1), 121-128. doi:10.1016/j.pec.2012.01.012

Primdahl, J., Wagner, L., & Horslev-Petersen, K. (2011). Being an outpatient with rheumatoid arthritis-a focus group study on patients' self-efficacy and experiences from participation in a short course and

one of three different outpatient settings. *Scandinavian Journal of Caring Sciences, 25*(2), 394-403. doi:10.1111/j.1471-6712.2010.00854.x

Rudan, I., Sidhu, S., Papana, A., Meng, S. J., Xin–Wei, Y., Wang, W., . . . Sridhar, D. (2015). Prevalence of rheumatoid arthritis in low–and middle–income countries: A systematic review and analysis. *Journal of global health, 5*(1).

Salmon, P. (2013). Assessing the quality of qualitative research. *Patient Educ Couns, 90*(1), 1-3. doi:10.1016/j.pec.2012.11.018

Salmon, P., & Young, B. (2018). Qualitative methods can test and challenge what we think we know about clinical communication - if they are not too constrained by methodological 'brands'. *Patient Educ Couns, 101*(9), 1515-1517. doi:10.1016/j.pec.2018.07.005

Scott, D. L., Wolfe, F., & Huizinga, T. W. (2010). Rheumatoid arthritis. *Lancet, 376*(9746), 1094-1108. doi:10.1016/s0140-6736(10)60826-4

Silverman, D. (2013). *Doing Qualitative R esearch* (Fourth ed.). Los Angeles Sage.

Smolen, J. S., Breedveld, F. C., Burmester, G. R., Bykerk, V., Dougados, M., Emery, P., . . . van der Heijde, D. (2016). Treating rheumatoid arthritis to target: 2014 update of the recommendations of an international task force. *Ann Rheum Dis, 75*(1), 3-15. doi:10.1136/annrheumdis-2015-207524

Sokka, T., Toloza, S., Cutolo, M., Kautiainen, H., Makinen, H., Gogus, F., . . . Pincus, T. (2009). Women, men, and rheumatoid arthritis: analyses of disease activity, disease characteristics, and treatments in the QUEST-RA study. *Arthritis Res Ther, 11*(1), R7. doi:10.1186/ar2591

van Eijk-Hustings, Y., van Tubergen, A., Bostrom, C., Braychenko, E., Buss, B., Felix, J., . . . Hill, J. (2012). EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. *Ann Rheum Dis, 71*(1), 13-19. doi:10.1136/annrheumdis-2011-200185

World Medical Association. (2018). Declaration of Helsinki. Retrieved from https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Zoffmann, V., Harder, I., & Kirkevold, M. (2008). A person-centered communication and reflection model: sharing decision-making in chronic care. *Qual Health Res, 18*(5), 670-685. doi:10.1177/1049732307311008