

EMPIRICAL STUDY

“Delivering knowledge and advice”: Healthcare providers’ experiences of their interaction with patients’ management of rheumatoid arthritis

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Abstract

Rheumatic diseases are often chronic and involve a lifetime of suffering. The focus of rheumatology care is to support patients to manage their lives and master their disease. Healthcare providers and patients have different views on the consequences of living with rheumatic diseases and patients are reporting unmet healthcare needs. There is a need to integrate providers’ perspective to develop the quality of rheumatology care. The aim was to explore healthcare providers’ experiences of their interaction with patients in their management of RA. Interviews with 18 providers from different clinical settings were analysed in accordance with the grounded theory method. A core category; Delivering knowledge and advice was found to be the most important task and involved providing the patient with information about the disease and appropriate forms of treatment. Healthcare providers’ attitudes and patients’ responses influenced the outcome of the delivery of knowledge and advice and three dimensions emerged; completed delivery, adjusted delivery and failed delivery. There were differences in the providers’ experiences in their interaction with patients as well as in reflections on their role as the delivering part. There could be difficulties in the interaction when patients’ expectations and preferences were not taken into account when giving advice. These findings highlight the importance of developing rheumatology care, as no provider or patient benefits if the delivery of knowledge and advice becomes a failed delivery. The healthcare organization must acknowledge the difficulties involved in the interaction with patients in their management of RA and find methods to develop a more person-centred approach to care.

Key words: *Grounded theory, healthcare provider, interaction, nursing, patient interaction, rheumatoid arthritis*

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Rheumatoid arthritis (RA) is the most common inflammatory rheumatic joint disease, affecting 0.5%–1% of the population (Alamanos, Voulgari & Drosos, 2006; Englund et al., 2010; Simonsson, Bergman, Jacobsson, Petersson & Svensson, 1999). Swollen joints, pain, impaired physical function and fatigue are common symptoms (Hill, 2006). Rheumatic diseases are often chronic and involve a lifetime of suffering. Living with a chronic illness means a changed way of life (Larsen, 2009). When suffering from a disease for which there is no cure, the person must relate to life in a new way (Sachs, 1996). The focus of rheumatology care is to support patients to manage their lives and master their disease (Ryan & Oliver, 2002). In recent decades, there have been pharmacological advances and new

possibilities for efficiently treating RA in order to reduce the risk of permanent joint damage and prevent functional impairment (Bykerk & Keystone, 2005). Non-pharmacological care comprises patient education and rehabilitation including information and advice about the disease, medication, exercise, finding an appropriate activity level, joint protection and non-pharmacological pain relief methods (Vlieland & Van den Ende, 2011). In rheumatology care, there has been a long tradition of working in multi-professional teams, in which the most common healthcare providers are nurses, occupational therapists, physicians, physiotherapists and social workers (Petersson, 2006). Key elements of patient satisfaction in rheumatology care are their experience of trust in the physician (Berrios-Rivera

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et al., 2006) and the healthcare providers' communication style, where patients welcome a more equal dialogue in the medical interaction (Lempp, Scott & Kingsley, 2006a; Ward et al., 2007). In patient-provider interaction, a central issue is to create shared meaning through good dialogue between the parts. This interaction between providers and patients in rheumatology care needs to be further investigated to increase the quality of care. The aim was, therefore, to explore healthcare providers' experiences of their interaction with patients' management of RA.

Method

Design and method description

An explorative design with the reformulated version of grounded theory (GT) by (Corbin & Strauss, 2008) was employed. The reformulated version of GT has been developed from symbolic interactionism that requires the individual to progress through social interaction and the creation of meaning (Blumer, 1986; Corbin & Strauss, 2008). The main purpose of GT studies is to generate concepts, models or theories from empirical data to explain the phenomenon under study. The collection and analysis of the data are intertwined in one process. Data collection begins with purposeful sampling followed by theoretical sampling. Theoretical sampling includes, in this study, sampling of the existing data when the theory is arising to look for aspects to confirm the arising theory or to object to the theory. The steps in the data analysis are open, axial and selective coding and throughout the process analytical tools, such as putting questions to the data, constant comparison and memo writing, are employed. Useful questions might be: "What is going on?" and "Who are the actors involved and what does it mean to them?" Constant comparison means comparing each situation with other situations to identify similarities and differences. During the analysis process, ideas, preliminary assumptions and theoretical reflections are written down in the form of memos to facilitate the generation of a theoretical model (Corbin & Strauss, 2008).

Participants and procedure

During winter and spring 2011, 18 healthcare providers working in four different rheumatology clinics in southern Sweden were invited to participate in the study. The clinical settings included one university hospital, two local hospitals in different counties and a specialist hospital for rheumatic diseases. The first author contacted the manager of

each clinic to provide information about and ask for permission to carry out the study. The manager then introduced the study to the healthcare providers and asked if they were interested in participating. The manager informed the first author, who then contacted the providers and agreed a time and place for an interview. The providers included nurses, physicians, physiotherapists, occupational therapists and social workers. The inclusion criterion for participating in the study was experience of working in a multi-professional team with patients diagnosed with RA. Purposeful sampling with regard to age, sex and years of work experience was used to obtain variation in experiences of the interaction with patients in their management of RA. The manager of each clinic was asked to consider the need for variation in the purposeful sampling. The interviews were done in a private room in the rheumatology clinic where the providers were working or in a private room that was desired by the provider. Each interview lasted between 30 and 80 min and was transcribed verbatim. The interview began with an open question: "Please, tell me about your experiences of the interaction with patients in their management of RA?" Follow-up questions were posed to deepen the answers and obtain rich meaning and experiences: "Can you tell me more about that?" and "What did you do then?" The providers who participated in the study comprised 15 women and 3 men. Their mean age was 45 years (28–64) and mean rheumatology experience was 10 years (6 months–27 years), see Table 1.

Analysis

The open coding began immediately after the verbatim transcription of the first interview by reading the text line by line to identify words, phrases and sentences that were labelled with codes that captured the meaning and accorded with the aim. The analysis began by asking sensitizing questions to tune the researcher into the message embedded in the data. Examples of sensitizing questions were: What is going on here? What are the issues and concerns? And who are the actors involved? By posing these questions to the data, the coding process moved to the next level of analysis—the axial coding process, where the codes were clustered into two higher categories; *Healthcare providers' attitudes* and *Patients' responses*. Theoretical questions were employed as an analytic tool when trying to identify processes and variations as well as understand the connection between the codes and categories. A frequent question was What would happen if...? The sensitizing and theoretical questions were then used along the process of

Table 1. Overview of healthcare providers' characteristics.

Informant	Sex	Age	Profession	Professional experience (in years)	Professional experience in rheumatology (in years)
1	Female	64	Occupational therapist	40	20
2	Female	43	Nurse	8	5
3	Female	47	Physiotherapist	23	5
4	Female	62	Rheumatologist	33	27
5	Female	32	Social worker	9	4
6	Female	54	Physiotherapist	27	27
7	Female	54	Nurse	28	7
8	Female	58	Occupational therapist	31	25
9	Male	40	Physiotherapist	13	8
10	Female	28	Nurse	3	3
11	Female	28	Occupational therapist	3	6 months
12	Male	49	Rheumatologist	24	16
13	Female	47	Occupational therapist	25	6
14	Female	38	Social worker	6	8 months
15	Female	54	Nurse	30	9
16	Female	29	Physiotherapist	6	4
17	Male	45	Rheumatologist	19	16
18	Female	36	Social worker	5	1,5

analysis. In the selective coding process, the core category, *Delivering knowledge and advice* emerged as the overall theme. The theory aroused when the core category was linked to both categories: healthcare providers' attitudes and Patients' responses. Theoretical sampling in the selective coding process led to three dimensions illuminating the outcome of the core category. Memos were used in every step of the analysis. In the beginning, a short memo was made after each interview to capture the first impression. In the open coding process, memos were used to track emerging categories. At a later stage, memo writing was important to find the core category as well as the three dimensions of the outcome of the delivery of knowledge and advice. After 15 interviews and analyses, no further information was obtained, indicating theoretical saturation. An additional three interviews were conducted to ensure that the information from the providers was theory based.

Ethical considerations

The study was approved by the Regional Ethical Review Board at Lund University (LU-2009/391). The study was explained to the participants both verbally and in writing and informed consent was obtained. They were assured that participation was voluntary and that they could withdraw without any need for explanation. Confidentiality was guaranteed and it was emphasized that none of the informants could be identified.

Findings

A theory was generated based on the healthcare providers' experiences of their interaction with

patients' management of RA. The core category, *Delivering knowledge and advice*, was the providers' most important task and involved providing the patient with a message, including knowledge and advice about the disease and appropriate treatment. The *Healthcare providers' attitudes* when delivering knowledge and advice constituted one cornerstone of the theory, while the other was *Patients' responses*. Healthcare providers' attitudes were dependent on factors such as adjustments, expectations, intentions, responsibilities and roles, while patients' responses depended on factors such as needs, reactions and responsibilities. The outcome of delivering knowledge and advice led to three dimensions: *completed delivery, adjusted delivery and failed delivery*. Circumstances of the healthcare organization became visible; legislation, economic aspects, accessibility, time and rheuma-team organization were parts that influenced the whole caring situation. Healthcare legislation was mentioned by the providers in relation to the patients' rights to be informed and to be involved in their care. Economic aspects were highlighted when providers expressed issues related to the rheuma-team organization and that the care could be time consuming. Accessibility was due to economic aspects as well as problems to get an appointment to a physician (Figure 1).

Delivering knowledge and advice

The core category, Delivering knowledge and advice, revealed healthcare providers' attitudes in the interaction with the patient. They wanted to teach the patient how to manage RA by providing him/her with advice and knowledge. The healthcare providers discussed this matter in different ways depending on their professional affiliation, but with

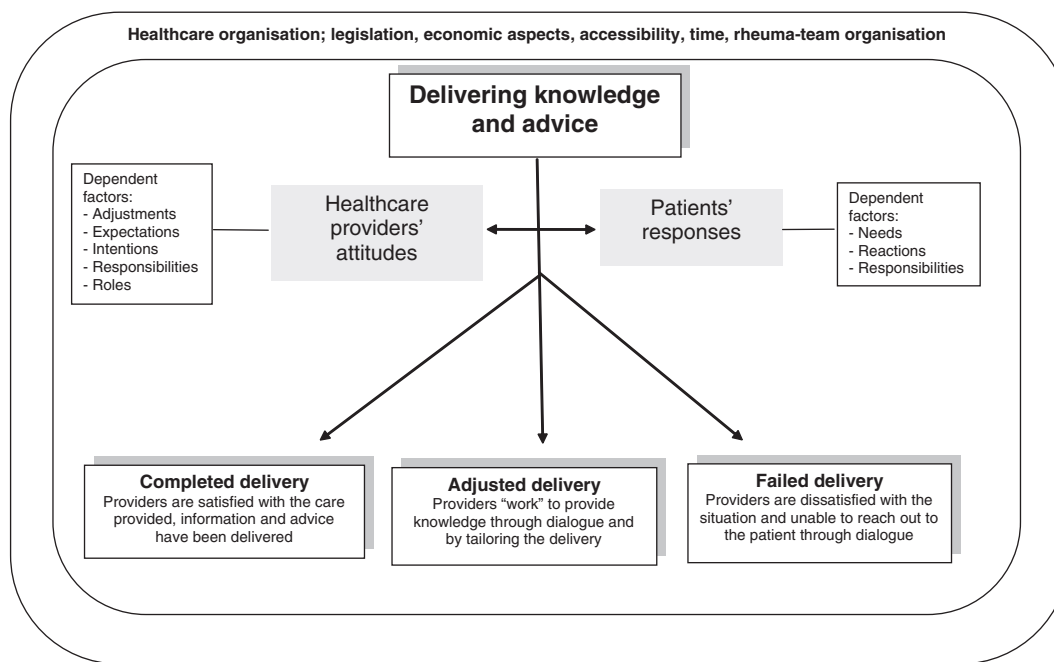


Figure 1. Healthcare providers' experiences of the process of delivering knowledge and advice through the interaction with their own attitudes and patients' responses and with three dimensions of the outcome.

the same intention—to deliver a message. The message involved knowledge and advice and the providers considered themselves an important source of information for the patient, who needed such guidance to manage the disease. There were healthcare providers who described their role as a management expert of and acted as the sender of the message while the patient was the receiver. Other healthcare providers mentioned a more receptive approach to the patient, tried to interact with him/her and tailored the advice or information to make it appropriate for the patient's needs. Patients' responses to the healthcare providers' intentions were important. The providers became frustrated when patients did not comply with prescriptions for exercise, medication or other advice, described as a "bad" response. The opposite situation when patients complied with the advice provided and reacted in a positive manner to suggested prescriptions was considered a "good" response.

Completed delivery

This dimension described completed delivery of knowledge and advice when healthcare providers were satisfied that their intentions and expectations had been fulfilled. A physiotherapist described a situation in which the patient reacted in a way that she deemed appropriate and in accordance with her own values:

"Many do not want to continue, they think it is awful to have to go to the hospital once a week (for

training) ... and I think that is sound ... really sound ... that they want to get out of here ... as soon as possible. Then they have understood that they have succeeded, when they feel that now I have to deal with it ... that is good".

Another way of describing the completed delivery was related to the healthcare organization. A provider with experiences from a team working with newly diagnosed patients reported the benefits of this form of delivery of the message. An occupational therapist stated:

"We have a special type of care ... what we call early arthritis care where the participants receive a great deal of information. So we hope that when they come to our clinic ... they receive their diagnosis, are prescribed a particular medication and have their first ... meeting with the team, then ... after they have received it ... they receive the information they require in order to know how to manage themselves".

When healthcare providers informed and gave the patient advice about the disease and treatment, they expressed that it was easier to interact with some patients, a physician stated:

"It is much easier to help a person who takes responsibility for the illness ... because it is easier to reach agreement with that person ... and how to proceed".

Delivering knowledge and advice was easier when the patient was complaint, active and assumed responsibility for the healthcare providers' advice. Completed delivery occurred when patients responded in the manner expected and their needs appeared to be fulfilled.

Adjusted delivery

Healthcare providers experienced the delivery of knowledge and advice as something ongoing and as an adjusted delivery. They described their experience as a process of reaching out and that they needed time to create a good relationship with the patient. Sometimes, the providers' way of delivering knowledge and advice was adjusted to match the patients' needs. A physician expressed:

"I believe that the biggest and most fundamental ... is the (patient's) personality ... and then in combination with ... how one can provide structured information that a particular individual can assimilate and understand. And then motivate ... motivate as to why we want to conduct specific tests and why we want to prescribe a certain medication ... at the same time not giving up (control) ... and we want it to work until we see them again at their follow-up visit".

Another form of adjusted delivery was bargaining as a toll to ensure cooperation that could include patients' wishes for a special treatment or different perspectives on the "right" treatment. The providers expressed the need to utilize all of their personal qualities to reach out to the patient when trying to deliver the message. A physiotherapist formulated:

"He clearly indicated that he was the one who made the decisions and this is what I do and I don't do such silly things that you do. And then it is a matter of—how can I deal with this particular patient? It is not easy. There is nothing in the textbooks so I think it's a question of what you have experienced previously, you must really use all the tools you've got at your disposal. So I made a compromise, a deal with him, OK you do one of your exercises and then you do one of mine ... I buy yours, you buy mine. We eventually had a programme that he accepted ... we negotiated the whole time."

Adjusted delivery involved thinking about patients' management of RA as a lifelong process. By this attitude, the healthcare providers demonstrated an expectation that the management of RA was never

ending and that interaction with the patients was a recurrent reality. The dimension was also defined as adaptation to the patients' requests but with a professional view of the disease. The responsibility issue in the interaction was described on an equal level with a clear goal of care and the outcome that the patient wished for. A social worker expressed:

"Then I think that many are moving in and out of the crisis all the time ... throughout their lives in different ways ... and suffering from a disease means being in grief, which does not go away just because you have pulled through .../the first ... like ... of accepting their disease and finding new ways. It makes itself known ... periodically, every day or for a period. But ... it often concerns the type of assignment I have ... from the patient ... what does this patient want help with ... what health status does he or she want to achieve when our contact comes to an end, have we attained these goals and so forth. We work through (the problems) together."

Adjusted delivery included a shifting interplay, sometimes through the adjustments made by the provider or through bargaining between the patient and provider. Providers expressed an emphatic attitude towards the patient who tailored delivery of the message, with the aim to involve and motivate the patient to be active in his/her own care.

Failed delivery

Failed delivery described situations when the delivering of knowledge and advice not worked satisfactorily. Healthcare providers experienced frustration when they did not fulfil their goals pertaining to the delivery of treatment and advice and also due to the patients' responses. Situations occurred when the providers did not reach out to the patient and there were difficulties with the dialogue and interaction that they described as a defeat. Frustration also arose when patients did not accept the treatment offered, seemed unable to understand the reasons for the advice or when the providers were unsure about how the patient complied with the treatment. A physician expressed:

"We have a man between 50–55, a farmer who has livestock ... he has an atypical seronegative RA ... that ... does not respond to anything, we are not sure how he takes the medication ... he knows that he has a disease and realizes that ... many times he can hardly get out of bed yet he manages to go to the animals ... he has no time to

come here for treatment. We try to make him understand . . .”

Providers also described frustration when they offered the patients a special teamcare intervention programme and the patient did not make the expected lifestyles changes or took responsibility. When patients did not respond as expected or comply with the intervention programme, the providers expressed dissatisfaction. A physiotherapist said:

“What we see is that she has reverted to the condition she was in when she first came (to rehabilitation). She does not change anything. She does not go back to work or change anything at home, but she is there for these four weeks and then nothing happens. And these patients . . . it feels as if we are not on the right level. Patients must take responsibility for themselves when they are taking part in training . . . it cannot only be that we are to feed them (with information) but they also have to make use of it somehow”.

The interaction between providers and patients was interfered when patients did not take responsibility for themselves or their actions. The issue of responsibility was also raised by providers when patients had no trust in them and/or the healthcare organization. There were patients who were well prepared and placed high demands on the care that caused difficulties in the encounter. A nurse commented:

“Most often it concerns medications . . . or medications that have not yet been released on the market . . . reading about research results . . . that is their way of grasping all information but they do not feel any better, at times it is like . . . it involves some anxiety too . . . they try to package it and assimilate it themselves . . . or . . . they instead make it more difficult, they have difficulty . . . it is as if they have no confidence or security. Such a patient feels misunderstood and does not obtain the information he/she wants . . . and we feel resigned . . . as there is no way that we can meet his or her needs”.

Failed delivery was described as a defeat, both with regard to the interaction between the provider and patient and in a professional way; the message was not completely delivered, due to the patients' response.

Discussion

Delivering knowledge and advice is the core category in healthcare providers' interaction with patients in

their management of RA. This includes knowledge and advice about the disease and appropriate treatment. The outcome of delivering knowledge and advice is dependent on providers' attitudes, in addition to patients' responses. The generated theory is also depending on the healthcare organization. The circumstances within the healthcare organization as legislation, economic aspects, accessibility, time and rheuma-team organization are building the frame of this phenomenon. These circumstances of the healthcare organization are also highlighted by Epping-Jordon, Pruitt, Bengoa, and Wagner (2004), who stated that the burden of chronic conditions is increasing and most healthcare organizations are not equipped to meet the shifting needs of care. They also suggested that the healthcare organization as well as the individual provider needs to make adjustments to produce positive outcomes (Epping-Jordan et al., 2004). Furthermore, there are differences in the attitudes of providers in terms of how they experience the interaction with patients. Similar results are described by Townsend, Adam, Cox, and Li (2010), however, from the perspective of patients, when they described both positive and negative medical consultations. A positive medical consultation, as experienced by patients, involved a relationship that focused on mutual respect and shared decision making, whereas negative medical consultation was an example of when the opposite occurred. The findings reveal that providers see themselves as experts or teachers as well as guides with a more person-centred attitude. A lack of awareness from providers of their own behaviour is revealed by Gorter et al. (2002), who concluded that patients were critical of the providers' behaviour and communication style. The findings illustrate the different outcomes of the delivery of knowledge and advice by means of the dimensions: *Completed delivery, Adjusted delivery and Failed delivery*.

Completed delivery incorporates satisfaction with the care provided from the providers' perspective. Differences in the content of the dimension occurred with regard to patients' responses. When patients acted in accordance with the providers' advice, the providers were pleased. If the providers offered a caring concept, such as an early arthritis educational programme, they seemed satisfied that they had developed an effective way of delivering the knowledge and advices. In this dimension, the providers' attitude and intentions were focused on giving information and they did not describe the need of emotional support that patients with rheumatic diseases experience, as reported by Zangi, Hauge, Steen, Finset, and Hagen (2011). On the other hand, Lim, Ellis, Brooksby, and Gaffney (2007)

claimed that patients were satisfied when their need of information was fulfilled. Maybe these discrepancies show the differences of patients' need of support. The completed delivery dimension illustrates that information transfer and the interaction between provider and patient was completed from the providers' point of view.

The dimension of adjusted delivery involves an awareness of the process of managing a chronic disease as reported by Arvidsson, Bergman, Arvidsson, Fridlund and Tops, 2011 and Kralik, Koch, Price and Howard, 2004. The providers demonstrate an awareness of the process of the management of RA that includes a lifelong commitment on the part of the patient. They try to reach out to and create a good relationship with patients through dialogue, to be supportive and encourage them to become involved in the care and show an awareness of patients' emotional need of support (Zangi et al., 2011). Patients' involvement in their own care implies a sense of control over the disease, and feelings of being understood are associated with patients' preferences in decision making (Ishikawa, Hashimoto & Yano, 2006; Ryan, Hassell, Dawes & Kendall, 2003). Adjusted delivery highlights the important issue of an equal dialogue in the encounter as presented by Lempp, Scott, and Kingsley (2006b). Patients' responses to the delivery of the message are defined in a reflected way, either by tailoring the delivery or the message, but also by adjustment to the patients' responses.

Failed delivery comprises situations that are not completed from the healthcare providers' point of view. Providers try to reach out to the patients but their attempts failed and they describe feelings of frustration when the dialogue not works. Failed delivery is dependent on how patients respond and some exhibit a "bad" response. The providers related this failure to the intervention offered, which not seem to fit all patients why someone else in the healthcare organization has to take care for these patients. Providers are dissatisfied with patients when they do not assume responsibility for the advice given or fail to change their lifestyle as recommended. Difficulties can arise in the interaction when healthcare providers do not take the patients' expectations and preferences into account when giving advice. Studies highlight the importance of incorporating patients' preferences into the medical encounter to increase the quality of care (Ishikawa et al., 2006; Kwok & Ibrahim, 2001; Ward et al., 2007). Failed delivery expresses situations when patients did not accept the offered medical treatment or accepted it with doubt, from the providers' view. The providers did not express why the patients did not accept the offered treatment.

According to Ward et al. (2007), patients' priorities could be an act of maintaining control over their situation by refusing medications and other interventions. The providers describe the failed delivery as a "bad" response that differed from the results presented by Ward et al. (2007). The failed delivery dimension could indicate a situation where patients' needs are not fulfilled and where they are dissatisfied. Providers describe failed delivery as a consequence of patients' responses and that sometimes the care offered does not match their needs or a trusting relationship is not created.

Methodological considerations

Credibility, dependability, confirmability and transferability were used to meet the methodological considerations of data collection and analysis (Polit & Beck, 2010). Credibility was ensured by describing the concordance between the data collection and use of analytical tools and through demonstrating the steps into the development of the theory. Dependability was guaranteed by the systematic and methodical approach to the data analysis and by the co-researchers, who were active and engaged in all steps of the analysis due to their previous experience of this method. Conformability and honesty towards the providers were important from the start of the research process, through the different stages of the analysis and to the presentation of a clear and comprehensive picture. This was achieved by identifying words, phrases and sentences from the providers and making continuous comparisons between data, codes and categories throughout the analysis process. The providers' integrity was respected throughout the research process. Another important consideration is the role of the researcher. In a qualitative study, the researcher becomes an integral part of both the research process and the findings and must be aware of the risk of bias and/or the assumptions that may be present (Hall & Callery, 2001). This was considered by the first author before the interviews, when writing down her preconceptions of the phenomenon. The co-researchers were involved in all steps of the analysis and on several occasions highlighted this issue. The transferability of the findings into clinical practice must be done in a similar settings: healthcare system, organization and culture. The present study represents providers' experiences from providers in four different clinical settings: one university hospital, two local hospitals in different counties and a specialist hospital for rheumatic diseases, to increase the experiences of the phenomenon. The variation in the providers' experiences was good with regard to years of experience and different care settings, but there was a

limitation in terms of sex, as only three men participated in the study. In healthcare settings in Sweden, there is a predominance of women, so the small number of men mirrors to the reality. The theory that emerged and is described in the model presents a picture of the providers' experiences of the interaction with patients with RA from a southern Swedish perspective.

Conclusion and implications

The core category, *Delivering knowledge and advice* explained healthcare providers' view of their role in patients' management of RA and their experiences of the interaction with patients. According to the theory that emerged, *Healthcare providers' attitudes* and *Patients' responses* are the cornerstones with three dimensions that result from the interaction between providers and patients. When providers experienced *Completed delivery*, they had a feeling of reaching out to the patient and that the patient understood and agreed with the information given. The providers did not reflect on whether the patient experienced the same satisfaction as they did with the completed delivery. *Adjusted delivery* indicated that the delivery of the message is a process that can be seen from either the providers' or the patients' perspective or as a process of the interaction between them. When the delivery of knowledge and advice not worked, *Failed delivery* occurred, a situation in which providers experienced dissatisfaction and frustration. New demands for modernizing rheumatology care, including demands from patients to be more active partners in care require a healthcare organization that puts the patients first and to reach the high goals of self-management patients. The providers need education and training to develop their communication skill. To meet these new demands, it will be necessary to discuss this issue throughout the entire healthcare organization and not just in the area of patient-provider interaction. Further studies are needed to evaluate the progress of rheumatology care from both a patient and a provider perspective, and with a person-centred approach. The present findings could be used in clinical as well as educational settings to create awareness about possibilities and challenges in patient-provider interactions.

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