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Patient-centred care in established rheumatoid arthritis



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ABSTRACT

Review of the evidence on patient-centred care (PCC) in rheumatoid arthritis (RA) shows that involving the patient as an individual – with unique needs, concerns and preferences – has a relevant impact on treatment outcomes (safety, effectiveness and costs). This approach empowers patients to take personal responsibility for their treatment.

Because clinicians are only able to interact personally with their patients just a few hours per year, patients with a chronic condition such as RA should be actively involved in the management of their disease. To stimulate this active role, five different PCC activities can be distinguished: (1) patient education, (2) patient involvement/shared decision-making, (3) patient empowerment/self-management, (4) involvement of family and friends and (5) physical and emotional support. This article reviews the existing knowledge on these five PCC activities in the context of established RA management, especially focused on opportunities to increase medication adherence in established RA.

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Patient-centred care in established rheumatoid arthritis

In line with rapid changes in our society, health care changes too. Fortunately, the efficacy, efficiency and effectiveness of treatments for chronic diseases more and more result in improvements in the quality of life and survival. Individuals increasingly prefer an active role in shaping their own lives, including how a chronic disease affects them. This process is catalysed by the rapid growth of the Internet, which offers convenient access to a wide range of health information, with interactive communication platforms [1]. Patients increasingly search the Internet for medical information, wish to have open communication channels with their health professionals, and are eager to actively participate in making important medical decisions [2].

Shift from physician-centred care to patient-centred care

These developments are influencing today's health-care systems. For decades, health-care systems were mainly organised from the biomedical perspective. Consequently, the needs of the clinician and the system took priority in the delivery of care to patients. In this model, the health professional was at the centre of the system – he or she had exclusive access to knowledge – and the patient was expected to comply with the instructions given by health professionals [3].

Further, the view on how to provide high-quality health care has altered [1,2].

Respecting patient's autonomy is not only ethically 'the right thing to do', it is essential, as it is the patient who has to live with the daily discomforts, the challenges of RA and the threat of disability.

High-quality care is now considered to be a collaboration of professionals and patients jointly working on restoring or maintaining the patient's health status [4,5]. Educated and empowered, patients will better manage their disease. Where professionals must stimulate and educate patients, they must feel obligated to work as partners with health professionals to optimise health ('participatory medicine').

In short, health care is changing from physician-centred care to patient-centred care (PCC), in which the health professional and the patient together decide what the best care will be [1].

Patient as part of the multidisciplinary care team

PCC is defined by the Institute of Medicine (a division of the National Academy of Sciences in the United States) as: '*providing care that is respectful of, and responsive to, individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions*' [6]. PCC places each patient at the centre of the health-care system, and it recognises the patient as a whole person with physical, psychological and social needs. Contrary to common belief, patient-centredness requires more than a respectful attitude towards patients or a personalised style of clinical interviewing. PCC is guiding patients with complete and *unbiased* information based on sharing the best available evidence and considering patients' cultural traditions, personal preferences and values, family situations, social circumstances and lifestyles. These individual characteristics may shine a different light on risks and benefits. As a consequence, patient's individual vision/experiences and physicians' visions (based on intensive education and experiences with many other patients) should be exchanged and integrated into treatment plans [7].

Bottom line; the underlying philosophy of PCC is the overall respect for patients as unique living beings in their specific social world, which implicates that patients should be treated as autonomous individuals who need to be viewed as full members of the multidisciplinary care team in order to assure that their wishes should be respected.

Patients need knowledge, skills and power

By definition of being the owner of their illness, RA patients typically cope with their illness on their own, in their own environment, most of the time in the absence of a clinician. Consequently,

they need knowledge, skills, as well as power to be able to monitor and manage their symptoms on a daily basis, and to partner with health professionals in optimising their health [1–3] as follows:

- Patients need knowledge about the disease and symptoms, treatment options and possible outcomes and knowledge about personal values and preferences
- They need skills to self-manage their disease, and to participate in medical decision-making (e.g., health literacy, self-monitoring, self-management and decision-making skills)
- Finally, they need power to believe in their capacity to self-manage their disease, and to be able to influence the treatment decision-making (i.e., self-efficacy) [1–3]. This includes factors such as believing that they have permission to participate and ask questions, having confidence in the value of own knowledge and ability to acquire medical knowledge, and self-efficacy to use self-management and decision-making skills.

Thus, besides knowledge and skills, the patients also have to be empowered to increase his/her self-efficacy, one of the main elements in Bandura's social cognitive theory [8]. Bandura defined self-efficacy as one's belief in one's ability to succeed in specific situations. Self-efficacy beliefs are cognitions that determine whether health behaviour change will be initiated, how much effort will be expended, and how long they will persevere in the face of difficulties [8].

Therefore, in light of this theory, it is essential to stimulate the perceived self-efficacy of patients to make them valuable partners in their own care. Patients need to be explicitly invited by the health professional to participate [9]. Improving self-efficacy also requires new skills for both patients and health-care providers [10]. This will require improving knowledge to patients and their families; improving health literacy; and finding effective means to facilitate skills essential for shared decision-making (SDM), goal setting, coaching and problem solving between health professionals and patients [11]. Education should finally also be focused on changing attitudes of both doctors and patients to overcome the power imbalance between doctors and patients in the clinical setting [12].

In this article, all examples to strengthen/stimulate PCC are based on knowledge, skills and power. These three elements are essential for the patient to be a valuable partner in his/her care process [1–3].

Evidence for effectiveness of PCC

Reviews on the effectiveness of PCC compared with more traditional health care show that the degree to which patients are more involved in their care has a significant impact on the quality of their treatment with regard to safety and effectiveness [7]. It might also benefit the health-care system in terms of financial performance [7]. Summary analyses of studies on interventions to better inform and involve patients in their care show improved experience with health care, lower dependence on health services, better adherence to treatment and, in some cases, measureable improvements in health outcomes [7,13,14]. This approach is agreed upon by the WHO (World Health Organisation) [15], which emphasises the importance of PCC.

PCC might also increase patient safety

PCC not only improves patient outcomes and satisfaction rate but might also improve patient safety. Although health care in general improves health of patients significantly, sizable numbers of patients are harmed each year because of medical errors [16]. An important contributor to medical errors is inadequate transitional care [17,18]. Patients with chronic conditions receive care that is often fragmented, incomplete, inefficient and, consequently, less effective [18]. Particularly in patients with established RA, this complexity is compounded by co-morbidities. Most patients with established RA acquire relationships with multiple professionals and institutions. Professionals should therefore collaborate across disciplines to make coordinated decisions, but should also encourage the patient to actively coordinate their care as constant factor in the health-care system. Patients can, for example, bring their own medication list, ask questions and involve themselves in test results.

Barriers for PCC

Although it is widely advocated that PCC should be incorporated in usual care, there are also barriers, which slow down the uptake of PCC in clinical care. Firstly, although PCC seems logically and morally well founded, and the evidence to support PCC is growing, still more evidence is necessary to demonstrate the (cost-) effectiveness of PCC. Secondly, terminology can be a barrier in the implementation of PCC. PCC is a 'container concept' for multiple different elements that refer to different medical processes in the medical consultation. This makes PCC difficult to operationalise in implementable and measurable elements [4,19,20]. PCC also requires additional competencies from the health-care professional. Clinicians should be able to judge the extent to which patients would like to be involved, and/or would like to make a shared decision. Finally, time constraints are often reported to be an important barrier to PCC [21]. A shortage of health staff leads to rituals and routines of practice, which impede the development of PCC in hospitals [22]. Surprisingly, although time constraints are commonly perceived as a barrier for the adoption of PCC in clinical practice, there is no evidence for a negative impact of PCC on the length of consultation or increase health-care costs [23].

Applying patient-centred care to improve medication adherence

As illustrated in this publication, patient-centred care (PCC) improves clinical quality and outcomes, and it might also decrease health-care costs. Besides, PCC might also decrease one of the underlying problems for poor health-care outcomes: medication adherence [24,25].

As in all chronic diseases, medication adherence is poor in patients with rheumatoid arthritis (RA). Although disease-modifying antirheumatic drugs (DMARDs) have proven to decrease the disease activity and radiological progression, adherence to DMARDs is not optimal and ranges from 22% (underuse) to 107% (overuse) [26]. This DMARD non-adherence has proven negative outcome results such as increased disease activity, radiological damage, loss of function and a lower quality of life [27]. Interventions to increase patient's medication adherence are therefore warranted.

At the moment, however, there is limited research on adherence interventions in rheumatic diseases, and the published studies showed inconsistent effect on adherence or disease outcome [28]. Patient-centred approaches may represent a foundation upon which to develop new medication adherence interventions and to enhance those that exist, but with the intent of also improving clinical outcomes, patient experience and satisfaction with medication use [108].

PCC to improve medication adherence

The principles of PCC are already embedded in the changes in terminology with respect to medication adherence. The oldest term to describe non-adherence was non-compliance. This term was intended to be a neutral alternative to earlier descriptions of patients who did not follow the clinician's advice, such as 'untrustworthy', 'uncooperative' or as proposed by Hippocrates, patients who lie about taking treatment. In short, compliance is a paternalistic conceptualisation of medication-taking behaviour, which disregards patients' perceptions on medication-taking [29]. Compliance is now replaced by adherence (the extent to which a patient's medication-intake behaviour corresponds with agreed recommendations of their health-care provider) in an effort to put the therapeutic relationship in its proper perspective. The concept of adherence places emphasis on a process, in which the appropriate treatment is based on a shared decision between the clinician and the patient and in which the patient's autonomy is respected. The difference between refusal of treatment and non-adherence is the patient's involvement in the decision-making process [30]. Thus, non-adherence occurs only if the patient does not follow treatment recommendations that are mutually agreed upon [31].

Unintentional and intentional non-adherence

Recently, two types of non-adherence have been conceptualized as 'unintentional' (e.g., forgetting medicines and miscommunication) and 'intentional'. Unintentional non-adherence

reflects a person's absence of ability and skills for taking medicines, including forgetting or poor manual dexterity, whereas intentional non-adherence is driven by a *decision* not to take medicines as prescribed [32–34].

Factors associated with adherence

Knowledge of factors associated with medication adherence in RA could provide possible targets for (improved) adherence interventions, and it might also help to identify patients who would benefit from an intervention. However, non-adherent RA patients seem hard to characterize by its (socio)demographic-, therapy- and condition-related factors [35]. These findings are confirmed in studies in other chronic diseases [36].

Although (socio)demographic-, therapy- and condition-related factors are not well associated with medication adherence, patients seem to adhere better when the treatment regimen makes sense to them: when the treatment seems effective, when the benefits seem to exceed the risks/costs (both financial, emotional and physical) and when they feel they have the ability to succeed at the regimen (self-efficacious) [25]. Thus, patients' knowledge, skills and power indeed seem to influence adherence behaviour.

According to the Necessity-Concerns Framework of Horne and Weinman [32–34], it is assumed that patient's decision to take medication is driven by a cost-benefit assessment. Herein, personal beliefs about the necessity of taking the medication for maintaining or improving health are balanced against concerns about the potential adverse effects of taking the medication [32–34].

Many studies underline the importance of addressing these necessity beliefs and concerns about medication to improve adherence. In RA, several studies assessed associations between medication non-adherence and necessity and concern beliefs about medication (measured with the Beliefs about Medicines Questionnaire (BMQ)). Mostly, stronger necessity beliefs were associated with better medication adherence, whereas some studies suggest that stronger concern beliefs were associated with decreased medication adherence [37–39].

Interventions to improve medication adherence should target these feelings. However, first, patients must feel safe to express their (non-)adherence, as this can be a delicate subject. The communication style must be open and non-judgemental, compliant to PCC and SDM. Motivational interviewing might be suitable to explore patients' medication needs, concerns and practical barriers. Then, patient's individual feelings about the necessity of the drug, patient's concerns and possible practical barriers can be explored. Possible barriers for adherence (not feeling the advantages of the medication, having concerns about the medication or experiencing practical barriers) can be explored with the patient (possibly using Fig. 1). To increase adherence, practical barriers can be resolved, and interventions to increase patient's beliefs about the necessity of the drug and to decrease patients concerns about the medication can be initiated. These interventions might be organised in the health-care setting, although e-health solutions can also be an alternative.

At the moment, there are no published studies on the effectiveness of an e-health intervention on medication adherence in RA. Studies in other chronic conditions show promising results [40,41]. However, the interventions are often complex, and the effect size is moderate. In case of forgetfulness, electronic reminders, especially SMS reminders, have been proven effective. Though long-term effects remain unclear, it seems logical that improving adherence can lead to optimised health outcomes [40].

In fact, when a patient does not reach his/her treatment target, a rheumatologist should always consider whether the patient is a non-responder or a non-adherer. In order to detect non-adherent patients, a rheumatologist can use electronic devices to measure patient's adherence (relatively costly) or use a validated questionnaire (e.g., Compliance Questionnaire on Rheumatology). Besides, clinicians can always discuss with the patients whether he/she experiences practical barriers (problems with taking the medication and forgetting medication), has doubts about the necessity of the drugs and/or concerns about their medication.

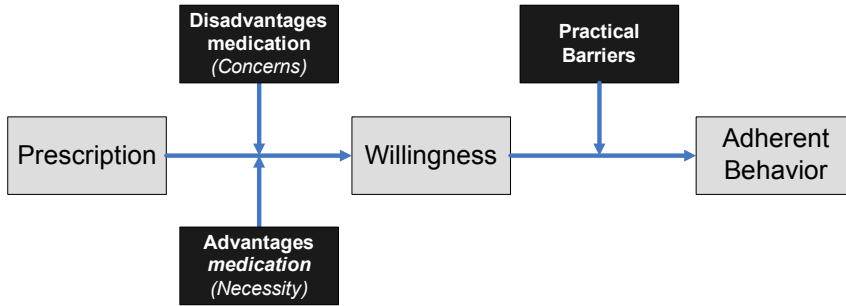


Fig. 1. Simplified model to concordantly discuss patient's main barriers for medication adherence: (a) intentional due to an imbalance between perceived benefits and concerns and (b) intentional due to practical barriers. During this discussion, patient's expertise and beliefs are completely valued [26].

Operationalisation of the concept of PCC

Multiple models and frameworks have been developed for describing PCC, with many overlapping elements [42–44]. This variety of frameworks leads to a heterogeneous use of the term PCC and measures to objectify PCC. Therefore, Scholl et al. have in 2014 synthesised the different dimensions of PCC, and they integrated these dimensions in a model [18]. This model describes the four main principles of PCC as essential prerequisite activities and essential enablers to implement PCC in daily clinical care. The main principles and activities are the focus of this article, and they are depicted in Fig. 2.

This model distinguishes four main principles of PCC:

1. *The patient is a unique person (Each patient has his/her own needs, preferences, feelings, cognitions, expectations and skills).*

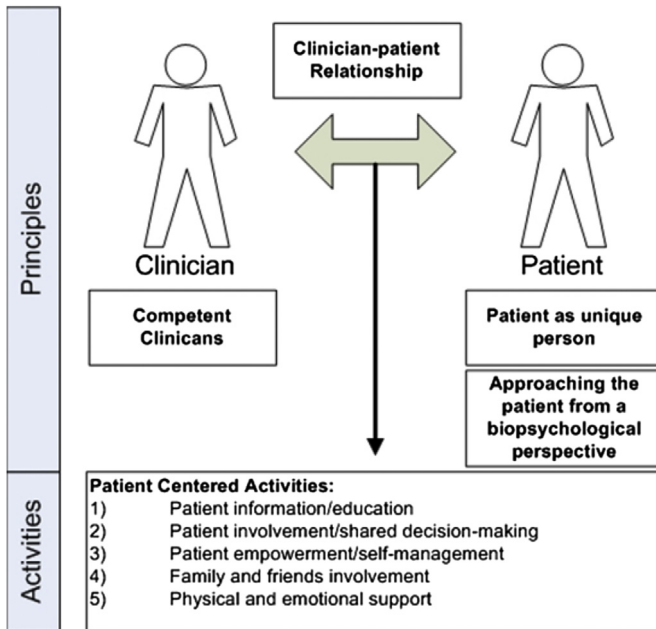


Fig. 2. Principles and activities of patient-centredness (adapted from Scholl [18]).

2. *Competent clinicians (Clinicians need specific competencies for PCC such as being respectful, empathic, tolerant, accountable and committed to the patient).*
3. *The clinician–patient relationship is the central component for PCC (Patients and physicians should have a partnership based on trust and mutual caring).*
4. *Biopsychosocial perspective (Understanding patient's illness within a broader framework by exploring the patient with his/her unique biological, psychological and social context).*

Based on these four principles, five PCC activities can be distinguished.

1. Patient information/education
2. Patient involvement/shared decision-making
3. Patient empowerment/self-management
4. Family and friends' involvement
5. Physical and emotional support

In this article, these five PCC activities will be elucidated in more detail.

(1) **Patient information/education**

Informing RA patients about the (consequences of the) disease and treatment options is a key element of providing health care. Especially, the uncertain disease progression, erratic course of exacerbations and remissions, the variable effects of rest, exercise and emotion, the management of often complex medication regimes, and the uncertainty of the prognosis and long term are essential items to be addressed. In addition, patients should be informed about how to access medical, psychosocial, physical and financial support [18]. Information provision is not only relevant at the beginning of the disease to explain the diagnosis but also relevant throughout the course of the disease in order to control the impact of the disease and its treatment on everyday life.

Recent studies have shown that RA patients have a high need for information, and that often these needs are not being met [42–44]. Patients state that information provision should not be limited to information about the disease and treatment but should also include emotional aspects and the impact on everyday life and focus on individual needs [44,45].

Physicians can only tailor information to the individual patient's needs, when patients are invited to share information (e.g., regarding symptoms and their impact on daily life, questions and concerns). With this mutual information exchange, the creation of the patient–clinician partnership begins. Possible questions to invite patients to share their thoughts are as follows:

- Which symptoms bother you most? Why?
- Can you tell me in your own words what you have understood and then, if necessary, I can help clarify

An example of integrating the view of the patients with regard to his/her condition is the application of PROs (Patient-Reported Outcomes), with disease-specific instruments as there is the RAID [46] (rheumatoid arthritis impact of disease) or generic instruments such as the short-form (SF)36 [47]. Online communication between patients and professionals is gaining popularity, and it helps to overcome a barrier to be able to reach the specialist at certain times [48].

The educational needs assessment tool (ENAT) can also support health professionals in assessing patient information needs. It is a self-completion questionnaire, which allows patients to prioritise their educational needs. The ENAT was developed by arthritis patients and their physicians, and it comprises the following domains: pain management, movement, feelings, arthritis process, treatments, self-help measures and support systems. It can be used to prepare a consultation in order to provide patient-centred and tailored education [45]. The ENAT can be obtained from the website <http://www.leeds.ac.uk/acumen/pages/research/ENAT.html>.

Interventions developed in the last decade also try to acknowledge this need for tailored information; there is a trend towards a more holistic and tailored approach with a greater focus on

behavioural, cognitive and emotional aspects [49]. In addition, information provision is more directly linked to educate skills to patients that enable them to monitor and manage their symptoms on a daily basis, that is, it is more integrated in self-management interventions and interventions to support SDM. This fits within the approach of PCC.

Low health literacy: a barrier to deliver information to patients

A barrier to PCC is low health literacy among patients [50–52]. Health literacy is 'the degree to which individuals can obtain, process and understand the basic health information and services they need to make appropriate health decisions and function effectively in the health care environment'. In order to be able to accomplish this, a constellation of skills including the ability to interpret documents and read and write prose (printed literature), use quantitative information (numeracy) and speak and listen effectively (oral literacy) is required [53]. Low health literacy is a significant problem, and it has been linked to poorer health outcomes [54] and medical costs [55,56].

In order to identify patients with low health literacy, various measurements are available such as the Rapid Estimate of Adult Literacy in Medicine (REALM) [57], the Test of Functional Health Literacy in Adults (TOFLA) [58], the Newest Vital Sign [59], the functional, communicative and critical health literacy scales assessment by Ishikawa et al. [60] and the Health Literacy Skills Instrument by McCormack [61]. An easy-to-administer self-assessment instrument that combines the measurement of computer skills with health literacy skills is the eHealth Literacy Scale (eHEALS) by Norman and Skinner [62].

Interventions for individuals with low health literacy are summarised by Sheridan and Haun [54,63]. Several discrete design features of the health literacy interventions that improved patient comprehension were, for example, presenting essential information by itself or first, presenting information so that the higher number is better, presenting numerical information in tables rather than in text, adding icon arrays to numerical information and adding video to verbal narrative. Furthermore, improving health literacy by focusing on self-management reduced emergency department visits, hospitalisations and disease severity.

Patient information and e-health

Although patient information is often provided as verbal and written instructions and demonstrations, patient information may also be provided online. The increasing accessibility and availability of the Internet, social media and related computer technologies provide new opportunities for the communication and delivery of information. More and more RA patients search the Internet for a diagnosis or treatment before consulting their physician [64,65]. In addition, also after consultation, patients search the Internet for confirmation, additional information and for information about the available treatment options [64,65]. Patients state that they visit the Internet in order to be an active participant in their health care, and also to be a responsible informed patient [64]. However, patients are hesitant to discuss their search for information with their rheumatologist because they fear it may be perceived as challenging by their physician [64].

Recent research demonstrated that seeking medical information with common search engines and simple search terms is quite complex and not always efficient, despite the increased use of Internet. Although the accuracy of the information provided is generally good, high health literacy levels are required, and key information is poorly covered and inconsistent [65–67]. Many patients perceive that online health information is confusing, and they have difficulties with formulating proper search strategies and evaluating the relevance and reliability [64,68]. Health-care organisations such as hospitals but also patient organisations could play a role in this by developing (online) tools that identify reliable and valuable information (i.e., carefully selected information). This information should be written on a level that is understandable for the majority of the population. Some arthritis foundations have reliable information online about treatments for RA, especially written for patients (e.g., www.reumafonds.nl and <http://www.rheumatology.org/Learning-Center/Glossary>).

Despite these emerging novel communication channels, only limited studies in rheumatology have focused on the use of these innovative information technologies. Rittberg, Dissanayake and Katz

performed a qualitative analysis of publicly available methotrexate self-injection education videos on YouTube [69]. This study demonstrated that only a minority of videos is useful for teaching how to self-inject methotrexate. However, in a follow-up pilot study, using a self-developed web-based video to teach patients to self-inject methotrexate followed by further in-person nurse education showed that the video was a very efficient manner of informing patients. The results of the video equal the standard teaching practice with regard to patient satisfaction, confidence for self-injection and knowledge while decreasing teaching time by 25% [70]. The video is available at <http://www.youtube.com/watch?v=jTn9YaQZn1U>.

Another method to provide information-using technology is to share audio recordings of the consultation with patients. Although studies regarding audio-recorded consultations have their focus in oncology and paediatrics, this technology can be a valuable innovation for rheumatology as well. A recent review noted that patients who received audio recordings have better information recall, clearer understanding and more active engagement in treatment decisions [71]. Furthermore, patients and their families value an audible record, because it allows them to share and reflect on what has been said. Nowadays, patients have also started to audio record their consultations using their phones, which has elicited strong reactions by some physicians [29]. Clinicians have mixed perceptions regarding the benefits, values and risks. Some clinicians accept and understand the benefits for the patient, whereas others see this as a threat and a consequence of distrust. A legitimate concern of clinicians regards sharing the recording with a wider audience or goes viral on the Internet. This virgin territory requires a new policy [72]. This new policy should incorporate recommendations such as (1) the physician should be informed before, (2) the recordings will not be distributed and/or altered and (3) if the physicians wants, he/she might receive a copy of the recordings.

(2) Patient involvement/SDM

SDM is defined as a patient-centred approach in which the clinician and the patient go through all phases of the decision-making process together. Based on the best available evidence, the clinician informs the patient on all treatment options and their harms and benefits. The patient expresses his/her values and preferences regarding these options. Together, they come to an agreement on what the best way is to proceed for this individual patient [73,74].

The benefits of SDM

Patient involvement in decision-making is considered beneficial, because patients have the right to self-determination [75], and the successful treatment of RA relies heavily on patients' self-management. However, situations can occur that patients and rheumatologists are not agreeing on the best treatment. There are four possibilities; the patient and the rheumatologist agree to a certain treatment or they agree to not follow a certain treatment. In these two cases, consensus has been reached about an optimal treatment in an SDM process. The problem occurs when the patient exercises the right to self-determination of which he/she is entitled to: he/she does not want a certain treatment proposed by the rheumatologist. In most cases, the proposed treatment will not be given, although some physician would feel perhaps irritated as physicians might experience this patient (from a physician-centred view) as a non-cooperative patient. The fourth possibility in clinical practice can be described as follows: the patient proposes a certain treatment, such as different medication/dose or a scan, but the rheumatologist does not agree. Then, it is essential that guidelines are followed, and best available evidence is discussed and explained to the patient to clarify the rejection and to avoid an unhappy patient. Care should be given within the boundaries of best clinical practice. Therefore, the treatment needs to closely fit in with the patient's values and lifestyle [76]. Furthermore, patient involvement is associated with better health outcomes, such as health status, self-management, adherence, coping behaviour and satisfaction with care [43,77–82]. The results are especially promising in chronic care [78] where the doctor–patient relationship is potentially a long-term one, and it requires partnership [83]. Finally, patient participation is important because studies show that patients' and rheumatologists' beliefs about illness and treatment may differ. This includes how they rank the potential benefits and side effects of available treatment options, how they

prioritise long-term outcomes and how they approach the escalation of treatment [84,85]. Therefore, high-quality patient–physician communication about the choice of treatment is important.

The importance of SDM in rheumatology is confirmed by the 2013 European League against Rheumatism (EULAR) recommendations, which states that ‘treatment of RA patients must be based on a shared decision between the patient and the rheumatologist’ [86]. Importantly, the EULAR international task force developing RA treatment recommendations noted that ‘decision-sharing by patient and rheumatologist is of such overwhelming importance that it should spearhead the recommendations’ [86].

Implementation of SDM

Although desirable, implementing SDM in daily clinical practice is challenging for both doctors and patients. Previous studies with questionnaires report that 30–40% of adults with RA report suboptimal SDM communication with their clinician. Younger and more educated patients seem to be more likely involved in medical decision-making [43,80,81,87]. In addition, patients with limited health literacy, limited language proficiency and lower trust in physician are associated with sub-optimal SDM communication [87].

For patients, it can be difficult to recognise that a decision needs to be made, and to actively participate in the process to come to an informed value-based decision [9,12,88]. They often have low confidence in their capacity to participate, a (perceived) lack of medical knowledge, are uncertain about which questions to ask and, above all, they perceive inequity in their relationship with their doctor.

Clinicians, on the other hand, may not desire or be comfortable with patient involvement due to a lack of time, self-efficacy and skills or due to indifference towards decision support tools [89–91]. Moreover, clinicians may overestimate their actual level of SDM [92], and some believe that patients do not want to participate in medical decision-making [93]. However, several studies have shown that RA patients have a high information need, and they want to be more actively involved in medical decision-making [9,43,80,81,94–98].

In daily clinical care, rheumatologists (and other team members) can facilitate SDM. As stated before, few patients are active participants by nature; most RA patients are not even aware of having a choice, and they are reluctant to participate due to a perceived power imbalance in the doctor–patient relationship. Therefore, the clinician, as an expert in complex medical decision-making and the one who is emotionally detached, should guide the decision-making process [99] (Table 1).

This process can roughly be divided into three phases (table 1):

1. Firstly, the patient has to be informed that there is a decision to be made, what the options are and that the patient can have a role in the decision-making process (i.e., acknowledging the relevance of patient participation and supporting patients in becoming involved to increase their confidence/self-efficacy to fulfil that role). This might be the most important step to take. The patient needs to know that there is often no single best choice, that his/her preference is of relevance (e.g., for

Table 1

Shared decision-making in three steps.

-
1. Initiating shared decision-making (SDM)
 - Stating the decision (and its options)
 - Explaining SDM and the relevance of patient participation
 - Exploring patient's preferred role in the SDM process and need for information
 2. Mutual information exchange
 - Detailed description of treatment options (*benefits/harms/impact in daily live*)
 - Eliciting patient's preferences (*based on values, expectations and worries*)
 - Determining patient's preferred role in the SDM process
 3. (Shared) deliberation of the options and (shared) decision-making
-

- increased adherence) and that, if relevant, doing nothing or keeping the status quo is also an option [100,101].
2. The second phase is information exchange. This includes the clinician describing all treatment options, the clinical harms and benefits of these options, and the possible impact on daily life. In this stage, it is important to give patients time to process all the information. Furthermore, patients need support in assessing how the treatment may affect their daily life, and in developing and expressing preferences, values, expectations and worries about the treatment. In this phase of information exchange, patient decision aids (PtDAs) may be helpful (see subsequently).
 3. Finally, when all relevant influencing factors are clear to all parties, the options can be deliberated, and a decision can jointly be made.

Exploring patient's role

During this decision-making process, the patient's preferred role should be explored. Research shows that most, but not all RA patients, want to participate. Most patients want to go through the full decision-making process with their physician, and others want to engage with the information but do not necessarily want to be involved in deliberation and decision-making [9,94,102–109]. What makes it even more complex is that patient's preference for involvement may change over time, and it may vary according to the situation he/she is in [9]. Moreover, patients who initially may be reluctant to participate may change their mind after the options have been presented [110]. Therefore, preference elicitation should be done at each decision and after presenting the options. This task requires empathic attention to the situation of the patient, and to the verbal and non-verbal cues the patient offers as the clinician invites the patient into the deliberative process [99]. If the patient decides to leave the decision-making to his/her doctor, the patient's values and preferences are still valuable to enhance the chance of success of treatment. Then, the doctor has the challenging task to decide in the patient's best interest; deciding which treatment fits in with the patient's personal values and lifestyle.

SDM also covers shared responsibility [101]. This specific aspect may be attractive to some patients and frightening to others [9]. Unexpected responsibility can be a burden, which is not desirable. To prevent patients from feeling abandoned to have to decide on their own, clinicians will need to make explicit that it is a shared process and not a derogation of responsibility [111].

Patient decision aids

To facilitate SDM, PtDAs can be implemented. In contrast to standard patient information materials, PtDAs state the decision to be made, and they help patients weigh the pros and cons of all relevant options. Furthermore, PtDAs help patients to clarify their values and preferences, and to prepare them for the SDM encounter. PtDAs come in many forms: on paper, video and/or (interactive) websites. They can be used before, during and in between clinical encounters – depending on the decision at stake and the patient's pathway. It is not yet clear which format is best. For a wide variety of treatment and screening decisions, PtDAs have repeatedly shown to have a positive impact on patients' knowledge about options, patients' risk perceptions and patients' feelings of being informed [82]. Moreover, PtDAs have improved patients' involvement in medical decision-making, and they lead to decisions that are more in line with patients' personal values [82]. PtDAs can have a positive impact on patients' satisfaction with decision-making, anxiety, adherence or health outcomes [82]. Although there is a clear need for increased patient involvement in RA, only a few studies on PtDAs in rheumatology have been reported, and the effects of the PtDAs have not yet been thoroughly determined [112–115].

Recently, a PtDA about RA medications, for use during the clinical encounter, was developed specifically for patients with limited health literacy [114]. By using five issue cards, the PtDA focuses less on reading and more on conversation and verbal exchange of information. A field test proved the PtDA to be effective in promoting a conversation and exchange of experience on the part of the clinician and values and preferences on the part of the patient.

As stated before, PtDAs come in many forms, including (interactive) websites. Web-based PtDAs have the advantage of being easily adjustable, which is especially relevant in RA where new treatments evolve rapidly. Furthermore, on websites, the information can be provided in portions,

adapting the amount and complexity of information to individual needs. In recent years, three studies on web-based PtDAs for RA have been reported [112,113,115], all with a different focus. One PtDA used animated videos and a value-clarification exercise to support treatment decision-making in RA patients who were prescribed methotrexate, but were unsure about starting it [112]. This PtDA focused on two options: to take methotrexate as prescribed or to refuse methotrexate and talk to the doctor about other treatment options. A pilot study among 30 participants reported improvement in patients' decisional conflict and knowledge after using this PtDA.

Fraenkel et al. recently developed a PtDA aimed to inform RA patients with ongoing active disease about the risks and benefits related to biologic therapy [113]. This tool is an interactive, web-based, computerised educational module with voiceovers. The main focus of this PtDA is on supporting accurate risk perceptions when patients face the decision to initiate a biological DMARD. Preliminary evidence showed that this tool increased patients' knowledge, patients' willingness to escalate care and the likelihood of making an informed value-concordant choice. The most recent study reports the effects of a PtDA that enables patients to compare multiple DMARDs on clinical aspects and possible impact on daily life [115]. This PtDA provides patients the opportunity to compare multiple specific DMARDs, perform exercises to gain insight in their preferences, worries and questions, and endorses patients to express these feelings and questions to the health professionals. A quasi-experimental study showed that users perceived a more active role in decision-making, and they perceived the final choice to be more consistent with their personal values.

All PtDA studies described earlier provide data that support the potential value of PtDAs in RA decision-making. All web-based PtDA studies report high acceptance rates; patients value the opportunity to process all the information at their own time and pace, as compared with during the medical encounter. However, the results should be interpreted as preliminary evidence – there is a need for clinical controlled trials to examine the impact of these tools in clinical practice.

Despite their promising effects, just implementing PtDAs is not enough to guarantee SDM to happen. Without a (natural) empathic doctor–patient interaction and involvement into partnership, a successful SDM process will not occur.

(3) Patient empowerment/self-management

In order to evolve from being a passive recipient of care to an active partner in health care, patients should develop knowledge, skills and power (see Table 2).

This can be established in self-management programmes. The programmes give patients with RA strategies and tools to better cope with the disease. Although self-management is often linked to patient education, patient education offers only information, whereas self-management interventions are more problem focused, action oriented and emphasise patient-generated care plans [117]. Self-management is therefore often defined as 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life' [118]. Successful self-management interventions for patients with a chronic illness require an integrated approach with not only active involvement of the patient and the health

Table 2

Characteristics of an empowered activated patient.

Source: 1st European conference on patient empowerment [116].

An empowered activated patient:

- Understands his/her health condition and its effects
 - Feels able to participate in decision-making with their (his/her) health professional
 - Feels able to make informed choices about treatment
 - Understands the need to make necessary changes to his/her lifestyle for managing the condition
 - Is able to challenge and ask questions to the health professionals providing him/her care
 - Takes responsibility for his/her health, and actively seeks care only when necessary
-

professional but also active involvement of the social environment of the patient: family, friends and colleagues [119–121].

Self-management in RA

The first self-management interventions in RA were introduced in the 1980s with the implementation of the Arthritis Self-Management Program (ASMP) [117]. This programme showed persistent reduction in pain and physician visits after 4 years. Self-efficacy was also increased in the self-management group [8,122,123]. Reviews of RA self-management programmes have shown that the explicit use of social cognitive therapy and cognitive behavioural therapy led to short-term significant improvements in function [124–126], although effects are rarely sustained. This might be a result of the fact that the need for support is very diverse.

Despite the potential effectiveness of self-management interventions, many patients have difficulty managing their chronic illness properly [119]. The access to self-management support might be hampered for various individual reasons such as depression, weight problems, difficulty exercising, fatigue, poor physician communication, low family support, physical symptoms, lack of awareness, transportation problems and cost/lack of insurance coverage [127]. Taking these different individual barriers into account, the conclusion is that each patient needs self-management support based on individual's needs.

Provision of self-management interventions

There are different types of self-management programmes, such as peer-led, lay-led and health professionals-led programmes, or a combination of these programmes. Most research with regard to self-management interventions evaluates group programmes delivered face to face, in contrast to the one-to-one approach by health professionals, which is the least evaluated delivery method.

Lay-led self-management programmes are becoming widespread in the attempt to promote self-care for people with chronic conditions. However, only small, short-term improvements in patients' self-efficacy, self-rated health, cognitive symptom management and frequency of exercise were published [128]. Arthritis self-management interventions provided by lay leaders (voluntary arthritis patients) showed positive changes both in the lay leaders and in course participants: less pain and more willingness 'to get on with life' was reported [129].

New technologies, such as Internet-based interventions, have shown positive results in health status measures (health distress, activity limitation, self-reported global health and pain) and in self-efficacy for up to 1 year [130]. An online peer-led self-management programme appeared to decrease symptoms, improve health behaviours, self-efficacy and satisfaction with the health-care system, and to reduce health-care utilisation up to 1 year [131].

Another possible viable solution is exploiting the potential of smartphone technology. Smartphone applications can be utilised without special training, often contain user-friendly visual graphics and voiceover animations. They can be provided in all languages with minor modifications to the intervention, and they are available at almost any place (including rural and remote areas) at any preferred time (so patients who work full time can also be reached). Nevertheless, the use of this technology is likely limited by age, gender and/or socio-economic levels, and its continuous utilisation may result in several problems, such as addictive use of the smartphone [132–134]. Furthermore, the existing medical applications available in online application stores developed for rheumatic diseases were not evaluated in any step of application development or discussed in the medical literature so far, which results in lack of scientific evidence on the effectiveness of such interventions [132] (Table 3).

(4) Family and friends' involvement

Patients with RA must cope with pain, stiffness, physical activity restrictions and also the psychological impact of their disease on their lives. Many of these adaptive challenges require help from others. Thus, rheumatic disease patients need an available and satisfying network of interpersonal relations on which they can rely on for both emotional sustenance and practical support. However, a

Table 3

Interventions with respect to family and friends' involvement.

Source: 1st European conference on patient empowerment [116].

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1. Involvement of informal carers in decision-making processes regarding health policy and services.
 2. Provide official recognition, financial support and social security benefits to informal carers.
 3. Provide professional home visits and regular communication between professionals and informal carers, including assessment of health and safety conditions and technical aids.
 4. Use the informal carers' experience of the cared-for individual in the training Of professional carers.
 5. Provide mental health protection measures for informal carers such as possibilities for flexible and part-time work, peer support, self-help, training and tools to evaluate carers' own mental health needs.
-

rheumatic disease also has an inevitable impact on the patient's family, social network and work. They also need to cope with disruptions in social life and work productivity.

Therefore, it is not only important to empower patients but to support families and other informal caregivers as well [133]. Examples of interventions to involve family and friends are depicted in Table 3. This empowerment of informal caregivers should be done by either the health provider or the empowered patient him/herself.

Informal caregivers may carry a large share of care provision. Supporting their role, training, and protecting their well-being have led to positive outcomes for the health of carers and the people they care for [117–135]. Informal caregivers can also be empowered by being invited to participate in meetings between the patient and the health professional. Furthermore, networks in local communities can empower informal caregivers (often families). Here, they have the opportunity to share knowledge, experiences and worries with other informal caregivers in terms of psychosocial support and training [116].

Informal caregivers often involve family. Although patients rely most on close family members as support (strong ties), weaker ties (less intimate, more distanced contacts) appeared more durable and less liable to loss over time than stronger ties [96]. Weak ties are especially useful when help from a stronger tie would be inconvenient, impractical or unwanted. Whereas intimate relationships with close ties decrease patient's feeling of independence, weak ties mostly less implicate burden or stigma about the receipt of help [134]. Moreover, weak ties are often based on reciprocating actions (payment, being friends), and therefore rendering the dependence/independence balance, which is experienced as less stressful, more durable and sustainable than other ties [135].

(5) Physical and emotional support

Besides informing, empowering and giving patients the right skills in order to participate in decision-making, PCC must also pay attention to patient's physical and emotional issues. The level of physical comfort that patients report has a tremendous impact on their experience of being ill [136]. In addition, emotional problems can be as debilitating as the physical effects of RA. Patients with RA are more likely to suffer from anxiety, depression and low self-esteem, and they have high levels of associated mortality and suicide, compared with the healthy population. The loss of the ability to carry out daily functions due to RA is also associated with the onset of depressive symptoms. Furthermore, the psychological effects of RA can extend to the partners, families, informal carers and patient's working environment [137].

Physical and emotional support interventions aim to support patient's physical state (pain management, foot care), emotional state (fatigue, depression), patient's lifestyle (nutrition, exercise, smoking), social functioning (work and social network), but also patient's safety (adverse events reporting, clean medical facilities, transitional care) [18,138].

Patient's physical and emotional status can also be improved by involvement in self-monitoring. In a British randomised clinical trial with 100 RA and psoriatic arthritis patients, patients received a training session where they were taught how to monitor their blood test results and when symptoms and side effects to report. In this study, the introduction of a self-monitoring programme resulted in

half the number of appointments with the rheumatology nurse with no detrimental effects to their clinical status of the patient (pain, fatigue, erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), disease activity) and with no increase in visits to the rheumatologist or general practitioner (GP). Patients with RA and PsA demonstrated that they can successfully understand and interpret their blood test results, and use this information along with reports of their symptoms and side effects [139].

Conclusion

PCC integrates the perspectives, understanding and preferences of patients into the delivery of health care. Essential for PCC is an effective clinician–patient partnership in which the clinician's recommendations are informed by an understanding of the individual patient's values, needs and life context (e.g., home life, job and family relationships). In addition, PCC takes into account the perspectives of the patient's family and other informal caregivers, when appropriate.

For the implementation of collaborative PCC, patients need knowledge (about treatment options available and of personal preferences and goals), skills (such as interventions to overcome low health literacy) and power (e.g., the believed ability to use this knowledge to influence decision-making in the encounter with the doctor). Patients will benefit when they are involved in their care, both at home and in clinical settings. Health information materials, PtDAs, self-management action plans and other 'technologies' to stimulate patient engagement are most effective when they supplement or augment, rather than replace, interactions between patients and professionals [140]. As patients take on new roles in health care, ongoing support from health professionals may become even more important.

PCC requires time and often a change in the mindset of both professionals and patients. Patient-centredness was associated with better outcomes and higher cost [141], although Stewart et al. imply that patient-centred practice improved health status, and it increased the efficiency of care by reducing diagnostic tests and referrals [142]. For either the short run or the long run, managers, patients and purchasers should determine whether the improvement in outcomes and patient satisfaction associated with becoming patient-centred is worth the investment in costs.

For successful implementation, Scholl et al. describe five enablers [18] as follows:

- Clinician–patient communication (*adequate competencies for patient-centred communication*)
- Integration of medical and non-medical care (*recognition and integration of non-medical aspects of care in health-care services*)
- Teamwork and team building (*importance of interdisciplinary and multiskilled teams*)
- Access to care (*timely access to conveniently accessible care*)
- Consideration and continuity of care (*coordinated continuity of care*)

Once implemented, it is expected that PCC may help improve the quality and safety of care, and it may ascertain an affordable health-care system for the next generations.

Vignette 1

In the Netherlands, a web portal was designed, which not only offers information on rheumatic diseases, treatments, available aids and support but also contains a personal secure login section, where patients can find their diagnosis, current medication and medication history, blood results, actual and previous disease activity, and outcomes on the quality of life-related instruments. All data are accompanied by written information and (where possible) charts and graphs to show the fluctuation in scores along a timeline using colours to compare the data to norm scores (www.reumacentrumtwente.nl).

Patients who were using this portal reported that they felt more involved in their treatment, and they had more knowledge about their treatment. One patient reported '*It would mean more involvement in myself. It concerns information about me, so I would like that very much (insight in electronical medical records)*' (male, 59 years, RA) [143,144].

Vignette 2

Researchers and clinicians from Canada developed a PtDA called the Animated, Self-serve, Web-based Research tool (ANSWER) for patients considering methotrexate for RA (<http://answer.arccanada.org/>). This instrument aimed to provide unbiased information on benefits and risks of methotrexate for RA, and to guide users through thinking if this is the 'right' treatment for them based on the information and their personal preferences. In a proof-of-concept study, this decision tool improved patients' decision comfort and knowledge. However, there was no effect on patient's perceptions of their ability to effectively manage and participate in their health care. One of the participants stated '*...I had done a lot of research about methotrexate on my own beforehand and I was really quite reluctant to use it. And the whole process helped me to, it didn't convince me to, I wouldn't say it convinced me, but what I would say is it helped me accept it was the best choice. (Lucy)*' [112].

Practice points

- Patient education should not only be focused on general information about the disease and treatment but should also be more tailored to patient's individual needs. An education needs assessment tool can facilitate the exploration of patient's information needs.
- Although shared decision-making (SDM) is considered beneficial and is recommended by the EULAR, the implementation of SDM in clinical practice is suboptimal. Clinicians should guide the patient in the decision-making process as few patients are active participants by nature. This process can be facilitated with patient decision aids.
- Many RA patients have difficulty to manage their chronic illness properly. New technologies, such as Internet and mobile phones, seem to be promising tools to improve patient's self-management.
- Rheumatic disease patients need an available and satisfying network for emotional and practical support. Interventions to involve patient's family and friends are therefore essential.
- Health information materials should supplement, rather than replace interactions between patients and clinicians.
- For the optimal implementation of PCC, patients need knowledge (e.g., about disease, treatment options, personal values and preferences), skills to manage their disease and to participate in medical decision-making and finally power to believe in their capacity to self-manage their disease.
- There is no evidence for a negative impact of PCC on the length of consultation or increase in health-care costs.

Research agenda

- Future research on PCC is essential to further develop, optimise and evaluate PCC. Aspects that should be covered are as follows:
 - Research focusing on the methodological aspects of PCC research aiming to standardise outcome measures and develop/validate instruments to assess these outcome measures
 - Research focusing on the (cost-) effectiveness of PCC interventions
 - Research that identifies optimal interventions to improve patient-centred care
 - Research that identifies specific populations and contextual considerations that would benefit most from a greater degree of PCC
 - Research on the implementation of PCC in clinical practice, including the education of health-care professionals on this topic

Conflicts of interest

All authors herewith declare that we have nothing to disclose.

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