

PATIENTS' PERCEIVED HEALTH INFORMATION NEEDS IN INFLAMMATORY ARTHRITIS: A SYSTEMATIC REVIEW

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DECLARATIONS OF INTEREST

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ABSTRACT

Objectives: To identify the breadth of the literature regarding patients' perceived health information needs related to inflammatory arthritis care.

Methods: A systematic scoping review of MEDLINE, EMBASE, CINAHL and PsycINFO was performed to identify relevant articles (1990 -2016) examining patients' perceived needs relating to health information in inflammatory arthritis. Data and themes were identified and categorised and risk of bias assessed.

Results: Twenty nine studies (11 quantitative, 14 qualitative and 4 mixed methods) from 4121 identified articles were relevant for inclusion. Most focussed on rheumatoid arthritis. Key findings included: 1) Reasons for seeking health information often focussed on gaining ownership over their condition and facilitating self-management. 2) Demographic differences in information needs were inconsistent, but women and younger patients generally reported more needs. 3) Desired information content was broad, and included targeted and practical information covering disease treatment and psychosocial wellbeing. 4) Preferred information delivery method was consultation with a Rheumatologist; however group sessions had advantages for psychosocial issues while written information provided useful supplementation. 5) Barriers to meeting health information needs were around timely access.

Conclusions: Patients with inflammatory arthritis have high information needs, desiring practical and individualised information. When developing strategies to meet patients' information needs, aligning patient expectations with delivery methods that are accessible, cost-effective and flexible may help to optimize patient outcomes.

BACKGROUND

Chronic inflammatory arthritides (IA), such as rheumatoid arthritis (RA) and ankylosing spondylitis (AS) are associated with pain, disability and reduced quality of life.(1) Care is complicated by disease flares and progression, complex therapeutic regimens, treatment side effects and impact on everyday life including physical, social and psychological wellbeing.(2-5)

Optimal management of IA is patient-centred and holistic.(6) This requires patient involvement and provision of information to allow patients to engage in shared decision-making to cope with their disease and actively participate in management. Understanding the patient perspective of their health information needs is essential to provide the right information at the right time and in the right place. Education programs in various non-rheumatological conditions have demonstrated a number of benefits including adherence to health regimens,(7, 8) self-care,(9) coping(10) and health outcomes.(11, 12) In rheumatological conditions, such programs have resulted in reduced pain, disability and depression.(13, 14) Informed patients are better equipped to share in management decisions and effectively participate in co-care, which may lead to improved outcomes and better adjustment.(15, 16) Previous studies in musculoskeletal conditions showed that effective patient education needs to be patient-centred and modified to individual needs.(17) Furthermore, the information deemed important by the patient may differ to that prioritised by the clinician or health service provider, due to a focus on different disease consequences and outcomes.(18, 19)

Identifying the patients' perspective regarding their health information needs may inform information provision, at the level of the individual clinician-patient relationship, and also more broadly, to inform health service development, policy and advocacy. Previous reviews of patient needs in inflammatory arthritis have focused on particular areas of information need only (e.g. around self management(20)) or assessed patient needs more generally without a specific focus on health information(21) and have often been limited to a single condition. Other reviews have also included studies addressing patient education more broadly, including those of educational interventions(13, 22). The aim of this review, in contrast, was to perform the first systematic assessment and synthesis of existing data specifically around patients' perceived health information needs relating to IA. This purpose design increases the likely utility of the findings to health program and policy development for people with inflammatory arthritis.

METHODS

A general, open review question was deliberately used to enable synthesis of an expected broad literature relating to patients' health information needs. We used a scoping review approach, as described by Arksey and O'Malley,(23) reinforced by systematic reviewing principles, to identify and analyse the evidence. This strategy was used to capture the breadth of the topic, and allow a wide-ranging exploration of the patients' perspective, map the existing literature and identify gaps in the evidence.(24, 25) This work formed part of a larger project examining patients' perceived needs relating to musculoskeletal health more generally.(26)

Search strategy and study selection

Four relevant databases (Medline, EMBASE, CINAHL and PsycINFO) were systematically searched for articles published from January 1990 to July 2016. Core search terms (MeSH and free text) were developed around four constructs: the consumer, health information, needs and patient perspective. These were then combined with search terms specific to IA and individual diseases (e.g. RA, AS). We considered a variety of dimensions of health information including why and where patients may seek health information, desired content, methods of delivery and perceived gaps in knowledge. The search strategy was developed by a multidisciplinary team including clinician researchers (Rheumatologists and Physiotherapists), a patient representative and an academic librarian. The detailed search strategy is provided as supplementary material.

The retrieved articles were reviewed for relevant titles and abstracts by four authors (KC, AL, MS, LC) using open-ended screening to capture relevant studies. One reviewer (KC) reviewed all identified articles, and three authors (AL, MS, LC) reviewed a proportion of the identified articles. Thus all abstracts identified by the search strategy were reviewed in duplicate. Full text of retained articles were assessed for relevance and to determine if they met the inclusion criteria, by: 1) concerning patients older than 18 with any form of IA (RA, AS, psoriatic arthritis, reactive arthritis, as defined by the individual studies); 2) reporting patients' perspective; 3) concerning patient needs and expectations related to health information; 4) concerning a study population comprising IA, whereby it was possible to extract data specifically for this population. Similar to the process described for title and abstract screening, two authors (KC and one of AL, MS or LC) independently reviewed each retrieved full text article. Thus the full text of all articles identified for potential inclusion were assessed in duplicate. Any disagreements around inclusion were resolved by discussion, and if uncertainty remained, by an independent third opinion (AW). The reference lists of relevant studies were manually reviewed to identify

further studies for screening. Studies were deemed appropriate for inclusion based on the relevance of their content, deliberately encompassing a broad range of study designs and methodology, both quantitative and qualitative, to adequately capture the scope of the literature in keeping with the intent of a scoping review.

Data analysis and synthesis

One investigator (KC) extracted data from the relevant studies. Studies were described according to publication year, participant number and source, age and gender composition, study design and primary aim. The principles of meta-ethnography were used to synthesise the data,(27) being a well-established approach in health-care research.(28) This technique involves induction and interpretation of data, via a process of mutual translation, which entails extracting words, themes or concepts from original studies as data, and translating these across several studies to produce a synthesis.(29, 30) Initially, one author (KC) developed a conceptual framework of themes and subthemes from the primary data and discussion within included studies. One senior rheumatologist (AW) independently reviewed the extracted data and confirmed themes aligned with the reported information. Two senior rheumatologists (AW, FC) as well as a patient representative reviewed the themes to ensure their validity and clinical relevance.

Quality assessment

Two reviewers (KC, JS) independently assessed all studies for likelihood of bias and methodological quality. Hoy's risk of bias tool(31) was utilised to assess the external and internal validity of cross-sectional quantitative studies. This tool was developed to examine study quality and risk of bias in prevalence studies. This tool has 10 questions that assess the external validity (questions 1-4) and internal validity (questions 5-10) of a study. Each question is scored either 'yes' (low risk of bias) or 'no' (high risk of bias). Thus for a study to be determined to be at a low risk of bias it was defined as scoring 8 or more "yes" answers, moderate risk of bias was defined as 6 to 7 "yes" answers and high risk of bias was defined as 5 or fewer "yes" answers. Qualitative studies were assessed using the Critical Appraisal Skills Program appraisal tool.(32) This tool has 10 questions that assists readers appraise articles based on appropriate research design (questions 2-3), sampling (question 4), data collection (question 5), bias (question 6), ethical issues (question 7), data analysis (question 8), research findings (question 9) and the value of the research (question 10). Each question is scored 'yes', 'no' or 'cannot tell' regarding the study quality and potential for bias. There is no overall score for the level of bias. Differences were resolved by discussion or a third reviewer (AW) if no agreement was reached. Results of quality assessment for the individual studies is shown in Tables 2 and 3.

RESULTS

The search strategy returned 4121 articles. Seventy-nine studies were identified as potentially relevant based on title and abstract screen. Fifty of these studies (63/3%) were subsequently excluded on the basis of full text assessment. Reasons for exclusion (note >1 reason applied to some studies) were most commonly not assessing health information needs, failing to report the patient perspective (i.e. individual patient-level data) or an inability to extract data specifically for the population with IA (i.e. where there was a pooled population of IA plus other conditions e.g. osteoarthritis). Twenty-nine studies were subsequently included in our review.(33-61) An adapted PRISMA flow diagram (Figure 1) demonstrates paper selection in more detail.

The characteristics of included studies are shown in Table 1. Most were from the United Kingdom or Europe(33-38, 41-50, 52-56, 58-61) with the remainder from the USA,(39, 51, 57) Australia(61) and Asia.(40) Most participants were recruited from ambulatory care Rheumatology clinics.(33, 34, 36-43, 46-48, 50, 52-61) Two studies included inpatients,(44, 55) while four recruited patients from disease registries or databases.(35, 45, 49, 51)

All studies analysed patients with either RA, AS, psoriatic arthritis or unspecified IA. Most studies involved patients with a diagnosis of RA,(33, 34, 36, 37, 39, 40, 42, 44, 46-52, 54-58, 60, 61) one involved patients with AS only(35) and the remainder included patients with a variety of IA (analysed together).(37, 38, 41, 43, 45, 53, 59)

Amongst the included studies were multiple study designs, although all were descriptive or non-analytic in nature. Study participants were generally recruited from ambulatory care with methods of recruitment predominantly being patient registries and databases, and convenience sampling. Eleven studies used purely quantitative methods; ten using written questionnaires (34, 36, 37, 40, 41, 49-51, 56, 57) and one using a quantitative questionnaire administered face to face by a researcher.(39) Some studies use validated measurement tools,(37, 39, 41, 44, 50) such as the Education Needs Assessment Tool, however most used customised questionnaires, in the absence of an existing tool that captured the individual study question. Fourteen studies used qualitative methods only. Four used moderated focus groups,(46, 47, 52, 59) seven one-on-one interviews(38, 42, 43, 53, 54, 58, 60), one a written questionnaire comprised of open ended free-text questions(48) and two a combination of focus groups and semi-structured interviews.(55, 61) Mixed methods were employed in four studies – three using mostly questionnaires including open-

ended questions interpreted using qualitative methods,(34, 35, 40, 44, 45) and one using a questionnaire and interview.(33)

Participant numbers in qualitative studies ranged from 15 to 173 and in quantitative studies from 10 to 1193. Where specified the mean age for participants was between 32 to 68 and proportion of female participants ranged from 11 to 100%.

Risk of bias in included studies

Quality assessments of included studies are presented (Tables 2 and 3). Study quality was variable. For quantitative studies quality scores assigned to individual studies as per the Hoy, et. al. assessment tool ranged from 4 to 7, with a median quality score of 6 (interquartile range 5-6). This would suggest on average the quantitative studies included in our review have a moderate risk of bias. Risk of bias in quantitative studies related to study population representativeness,(34, 37, 39-41, 49-51, 56, 57) non-response bias,(36, 37, 39-41, 45, 49-51, 56, 57) validity of measurement tools(34, 36, 39, 40, 49, 51, 56) and adequacy of follow-up time.(34, 36, 37, 39-41, 45, 49-51, 56, 57) In qualitative studies, risk of bias was associated with recruitment/data collection(33, 35, 43, 44, 48, 52, 53, 55, 58, 60) and researcher bias.(33, 35, 42-44, 47, 48, 52-55, 58, 59, 61)

Results of review

Five key themes regarding patients' perceived health information needs about IA were identified: 1) Reasons for seeking health information; 2) Demographic differences in health information needs; 3) Content of health information; 4) Preferred information delivery and communication modes; and 5) Barriers to meeting health information needs. Results from individual studies are provided in Tables 4, categorised by theme.

Reasons for seeking health information

Five qualitative studies identified factors related to motivation for seeking health related information.(33, 38, 46, 52, 58) Factors were mainly around patients' desire to gain control or ownership over their health(38, 52, 58), engage in care(38, 58), develop strategies to live with their disease(46, 52, 58) and prepare for the future.(33, 46)

Demographic differences in health information needs

Ten studies (7 quantitative and 3 qualitative) identified differences in patients' perceived health information needs based on demographic factors.(35, 37, 39, 40, 48-51, 56, 61) Where gender comparison was analysed, five studies found females had higher information needs,(35, 37, 39, 40, 51) while two found no gender

difference.(49, 50) Similarly, three studies suggested younger patients(35, 49, 51) tended to have higher information needs, but one did not.(37) Although three studies found that higher levels of education and current employment were associated with stronger preferences for information(39, 40, 56) three others did not.(37, 49, 50) There were no consistent associations between disease duration,(37, 49, 50) disease activity or physical functioning(37, 40, 49) and information needs.

Patients' perceived needs regarding content of health information

Twenty three studies (12 qualitative and 11 quantitative) identified patients' needs related to content of health information.(33-37, 39-51, 53, 55, 58, 59, 61) Most desired a general explanation of their diagnosis(41, 45, 46, 50, 51, 59, 61) but with less emphasis on detailed factual information about disease pathophysiology and course.(35, 36) Information about prognosis(33, 42), and for women, about pregnancy,(61) were specifically raised. Twelve studies found patients expressed a need for information about pharmacological management including rationale, side effects and alternatives.(33, 34, 36, 40, 43, 46, 50, 51, 53, 58, 59, 61) Participants in six studies wanted information about exercise and physical therapy including potential positive or negative effects on joints, specific exercise instructions, assistive devices and access to physical therapy services.(33, 45, 47, 49, 50, 59) In addition to information on medical management, participants in twelve studies also placed moderate importance on information about psychosocial care and self-management strategies,(33, 35, 36, 41, 42, 44, 45, 48-50, 59, 61) such as coping with the emotional impact of disease,(33, 48, 49) social support,(36, 42, 49) and self-help.(33, 48, 49, 59) In particular coping with disability and pain (33, 44) and optimizing function and performance in everyday activities(36, 41, 44, 45, 59, 61) were raised, with a need for practical information, targeted to their situation.(35, 44, 61) Other identified areas of information content need related to pain management,(33, 50) relevant facilities(49, 59, 61) and new research in their disease.(35, 36)

Ten studies commented on the amount of information desired(33, 36, 37, 39, 41, 45, 48, 53, 55, 58) and although there was generally a high demand for information, needs varied. Patients in four studies were concerned "too much" information, particularly negative information, could generate anxiety.(33, 43, 55, 58)

Preferred information delivery and communication modes

Sixteen studies (12 qualitative and 4 quantitative) studies identified patients' preferences for various modes of information delivery.(33, 35, 36, 38, 41, 43, 44, 46, 48, 49, 52, 53, 57, 59-61) A Rheumatologist was often the preferred information source, particularly for medical information (i.e. disease, treatments), with a preference for face-to-face delivery.(33, 36, 57, 60, 61) However a variety of different

sources, as described below, were often utilised by individual patients (36, 41, 53) and other sources and modes of delivery were deemed to have strengths for certain types of information.

For example, one-on-one communication was favoured for disease-based information,(33, 36) but was also important for emotional and quality of life information(33, 48) and among non-English speakers.(46) Written information or leaflets were a popular complement to clinical encounters for additional or more detailed information, and as a memory aid.(33, 35, 38, 60) Written material was deemed useful for health services information.(49) Videos were viewed as useful for sharing information and visual cues.(33) Patients from non-English speaking backgrounds identified bilingual educational CDs as useful and more accessible than written material.(46) In the more recent studies patients accessed the Internet regularly, and found it a valuable source,(41, 53, 57, 61) particularly for patients in rural settings.(61) Some patients raised concerns regarding quality, utility and high volume of material.(43, 52) Group sessions were also an acceptable format for communicating information around psychosocial and self-management issues, with a major benefit of sharing ideas, and learning from others with a patient perspective of living with their disease.(33, 35, 52)

The context of information delivery was also identified as important. Patients expressed the need for positive and optimistic information(33, 35, 52) and information tailored to their specific needs(33, 44, 48, 59). They also valued adequate time to obtain information, timely access and patient centred communication styles such as understandable terminology and open language.(38, 48, 59, 60)

Patients' perceived barriers to meeting health information needs

Barriers identified by patients to meeting their information needs were identified in six qualitative studies.(33, 35, 46, 47, 52, 61) Barriers included lack of, or inconsistent knowledge by clinicians.(35, 47, 61) Poor access to, or hesitancy to use reliable information sources and the lack of ongoing information over the disease course were also raised as issues.(33, 35, 48) Difficulties with communication due to a language barrier was problematic for non-English speaking patients.(46)

DISCUSSION

This review found 29 studies identifying factors related to patients' perceived health information needs in IA. The key themes identified were: reasons for seeking health information, demographic differences in needs, preferred content and delivery modes and barriers to meeting health information needs.

We found that patients sought health information to gain ownership over their condition and facilitate self-management and co-care. Similarly, in other patient groups, health information seeking relates to supporting adjustment to illness, developing coping strategies, involvement in health decision-making and guiding health related behaviours.(62, 63) Most studies in this area however, have been in patients with malignant disease, where issues of chronicity and progressive disability may be less relevant.

In the reviewed studies females, younger patients and those with higher educational backgrounds tended to report more needs. This is consistent with studies of other chronic diseases(64) including rheumatological conditions such as osteoarthritis(65) as well as general medical,(66, 67) cardiology(67, 68) and oncology(69) patients. These patterns however are not sufficiently robust to generalise and drive decisions regarding information provision on an individual or broader scale. Further, the disproportionate gender balance in the included studies may bias our findings regarding gender preferences for information.

Desired content of health information was broad among patients with IA. It included treatment information, both pharmacological and non-pharmacological, self-management, especially around pain and disability, and dealing with the emotional and psychosocial impacts of disease. These content needs are similar to those identified in other populations with rheumatic conditions(70, 71), as well as chronic non-rheumatological conditions.(64) In the studies reviewed, patients emphasised the need for information to be targeted, practical and relevant to daily disease management and quality of life. This corresponds with previous studies of educational interventions in RA where patients commonly criticised information for being too general or irrelevant.(44, 48, 72) Overall, information needs were high, and patients often had unmet needs. Some patients however were concerned about "over-education" provoking anxiety; although being well-informed has not objectively been shown increase anxiety(39), this may be a relevant consideration for some patients and highlights that information delivery needs to be titrated and delivered in a manner that is appropriate to the individual.

Direct consultation with a Rheumatologist was the preferred information source, particularly relating to disease or treatment. A major advantage of a one-on-one approach is flexibility and ability to focus on individual needs.(73) In other medical conditions similar preferences have been reported, with physician consultation being valued for clinical expertise and experience.(74) Nevertheless we found group sessions and interactions with a non-professional had particular advantages for psychosocial and self-management issues. This is consistent with rheumatology patients' satisfaction with previous interventions, including "patient ambassadors", conference-style multidisciplinary educational interventions, and group education focusing on peer-learned problem solving and self-management skills.(75-77) Other forms of information provision provided supplemental benefit, with written information most highly rated. Perceived benefits of written material in previous studies were the ability to refer back and consolidate understanding.(78-80) However, content needs to be appropriate and patient-directed, and presented so patients are able to read and understand it.(79, 81) These considerations are particularly important when designing decision aids related to interventions or diagnostics.(82) The Internet had mixed reviews but appears increasingly popular as an information source, corresponding with greater accessibility in recent years.(83) A similar pattern is evident in studies of primary care and other patient groups.(74) Patient concerns around online material often related to reliability and amount of information available, mirroring clinicians' concerns.(84) Indeed, these may be well founded with studies suggesting quality information about arthritis on the Internet is scarce and time-consuming to find.(85, 86) Despite this, specifically designed websites aiming to provide arthritis-related information were highly rated on patient evaluation.(52, 87, 88) The ability to update information regularly, overcome geographic and time barriers to information access, and adapt based on patient feedback are significant advantages of online resources.(52)

Given various information delivery methods are viewed positively by patients and are complementary, a multi-faceted approach may be of greatest benefit. A significant gap noted in our review was that patient views on the role of the general practitioner and particular allied health practitioners as sources of information was not commonly assessed or raised by patients. Perceived lack of specific knowledge in a relatively specialised area may be one reason for this,(35) or alternatively patients may not be aware of the potential role of such health practitioners as information sources. Given barriers around timely specialist review, pursuing further investigation of the role of other health professionals as an information source would be of interest. In addition, very few studies we identified looked at information delivery preferences in terms of effective communication, use of language and health literacy which will be an important avenue for further research.

Patients identified the main barriers to meeting their information needs were inability to access desired information or preferred sources in a timely manner. This is similar to limited literature in other patient groups.(74) Overcoming barriers to access requires consideration of patient preferences balanced against efficacy, cost and feasibility of various methods of information provision. Meeting patients' changing information needs over time is challenging as information requirements depend directly on patients' current context and situation.(64) This is particularly relevant in IA, as disease activity fluctuates, disability progresses and the rapid development of new treatments generate the need for updated information. This may contribute to why many educational programs in RA are initially beneficial, but have limited long-term effects.(13) Most patients in the included studies had established disease and investigating how information needs vary at different disease stages may help target information provision over the disease course. Lack of specific knowledge among health professionals, in areas such as exercise advice, was also an issue identified in the included studies. This corresponds with previous research of patients with arthritis who despite believing exercise to be an important factor in treatment, lack certainty about what and how to perform exercises safely.(89) Other barriers that may not be identified by patients, such as lack of knowledge about available health information should also be considered.

Limitations of this review include the diversity of the individual studies regarding primary aims, study design, patient population and quality. Despite a comprehensive literature search, very few studies specifically assessed health information needs from the patient perspective as a primary aim. Thus, data were often extrapolated from results arising from different study questions. Although this still resulted in the presentation of relevant primary data for our study question, the data available for us to review and include was limited to that selected for publication by the authors of the primary studies, thus potentially introducing a source of bias. Primary studies that directly address our study question are required to overcome this issue should this review be replicated in the future. Researcher bias may have arisen in our own data extraction and meta-synthesis process, however we attempted to minimise this risk by a second author independently overseeing the data extraction and meta-synthesis processes. Variability in quality of the included studies also introduces the risk of bias. In particular, styles of recruitment and non-response rates limit overall generalisability, and most studies did not use validated tools to collect information. Most of the qualitative studies had small numbers and captured mostly females aged over 50 with established disease. Although this is a common demographic with RA in particular, it may limit generalisability of our results to other less well represented patients. Furthermore, most studies were conducted in Western Europe and

therefore best reflect their patient populations and health systems. Further studies, particularly qualitative, including a broader demographic with consideration for low and middle income settings would more widely represent patients with IA and better inform service delivery and policy initiatives. Studies included mainly patients with RA, and needs may differ in those with other inflammatory arthritides, although there were no clear differences between RA alone, mixed cohorts or other IA in available studies.

Strengths of this study include a comprehensive search strategy and summary of the current evidence base. Despite heterogeneity between studies, common themes and views were observed across multiple cohorts, lending construct validity to the results. We included both quantitative studies, providing breadth of data, and qualitative studies, providing important deeper insight into the consumer perspective.

It is recognised that providing relevant health information and meeting patients' information needs are key components of patient-centred care. It enables patients to engage with disease management, facilitates coping and reduced stress and improves adherence and thus health outcomes.(64, 90) This review has identified several patient priorities around health information for patients with IA and important areas for further research. Encouragingly, recent clinical practice guidelines in IA emphasise effective information provision for patients, and published priorities and recommendations align well with the patient priorities identified in our review.(91, 92) These need to be taken in conjunction with other factors affecting health information needs and seeking behaviour, such as patients' health knowledge, health literacy and other social factors.(93) This will inform the development and evaluation of accessible health information delivery to those with IA, in a way that is patient-centred, cost-effective and able to meet changing and increasingly complex health needs.

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Figure 1: Modified PRISMA flow diagram

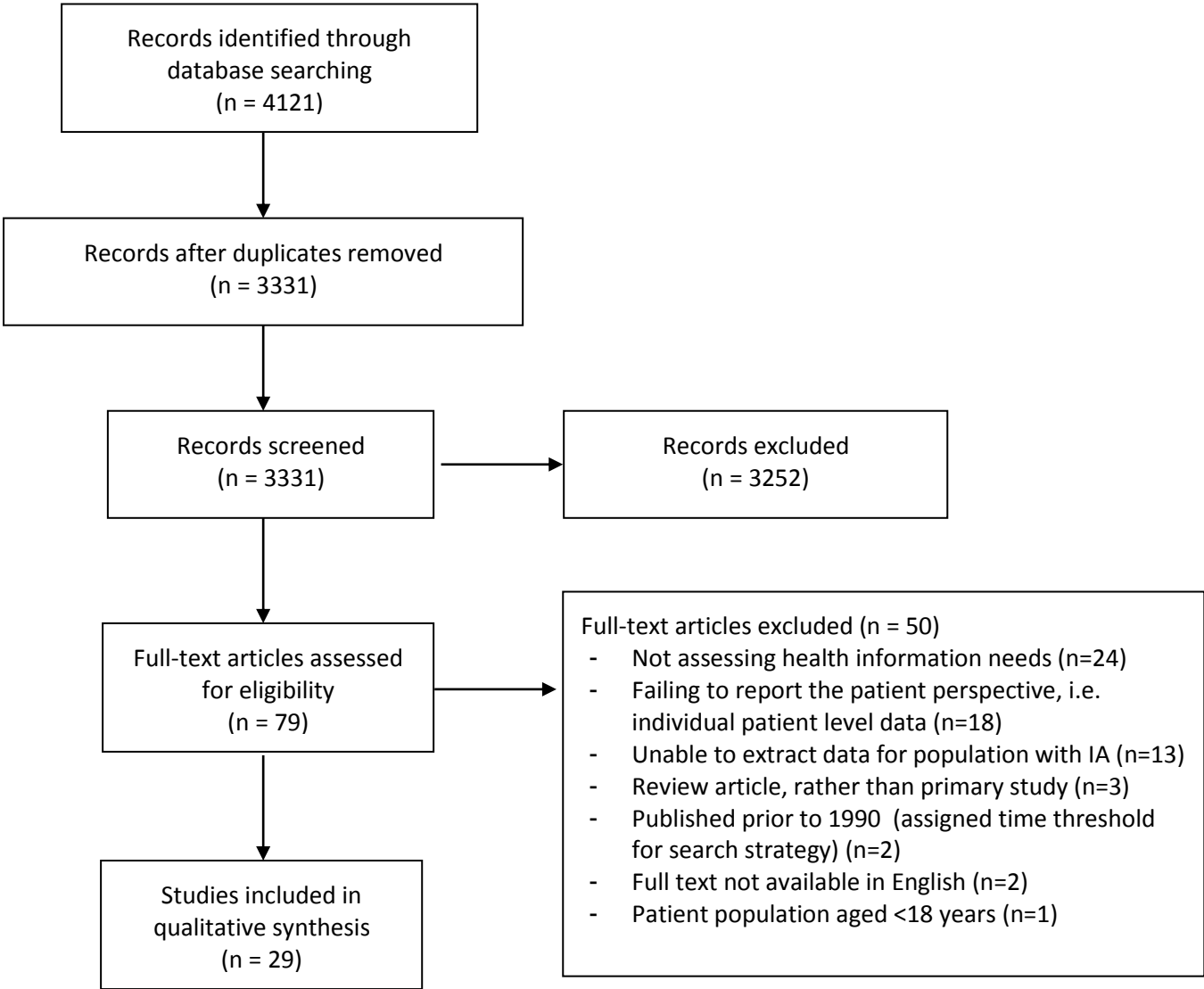


Table 1: Descriptive characteristics of included studies

Study details	Number of participants	Study design/methods	Participant source	Age and gender	Diagnosis	Primary study aim
<i>Rheumatoid arthritis (RA) only</i>						
Ackerman (61) (2015) Australia	27	Qualitative interviews and focus groups plus validated questionnaire to assess educational needs	Recruited via rheumatologists, obstetricians, child/maternal health nurses, peer support groups and arthritis consumer organisations	Median age 32 100% female	RA (physician diagnosed)	To determine the need for (and preferred mode/s of delivery of) information regarding pregnancy, post-natal care and early parenting among women with RA
Barlow(33) (2002) England	82	Quantitative written questionnaire with random subsample (n = 15) undergoing semi-structured phone interview	Outpatients from a Rheumatology clinic at a regional hospital	Mean age 59 86% female	RA (1987 ARA criteria)	To examine patient preferences for psycho-educational intervention addressing education, self-management and consequences of RA
Berry(34) (2008) UK	54	Self-completed mainly quantitative written questionnaire	Outpatients on DMARDs from 2 hospital Rheumatology clinics	Mean age 62 69% female	RA (definite or possible RA by ARA criteria)	To assess confidence in nurse prescribing including extent and type of information that should be included
Cunha-Miranda (36) (2010) Portugal	223	Quantitative questionnaire administered in person or via phone	Outpatients from several hospital Rheumatology departments	Mean age 55 82.5% female	RA (ACR criteria)	To determine the principle sources of information about RA, what unmet needs exist and level of patient involvement in therapeutic decisions

Fraenkel (39) (2001) USA	100	Interview consisting of 4 quantitative questions from the Information Preference Seeking Scale	Outpatients from a rheumatology community practice	Mean age 68 73% female	RA (definition NS)	To quantify preference for disclosure of information among patients with RA and to examine sex-specific correlates of information preference
Funahashi (40) (2012) Japan	165	Quantitative self-completed written questionnaire	Outpatients from single hospital outpatient clinic	Age NS 84% female	RA (clinic diagnosis)	To assess expectations of treatment including information wanted before starting a new treatment
Hardware (42) (2015) UK	16	Qualitative semi-structured interviews	Outpatients recruited from a larger multicentre randomised controlled trial	Mean age 61 50% female	RA (definition NS)	To evaluate the usability of the Educational Needs Assessment Tool in clinical practice and to establish whether patients perceive they are getting an equally good education service for their needs.
Kaariainen (44) (2010) Finland	70	Quantitative written questionnaire (Patient Education Quality Instrument) with two added open ended questions	Hospital inpatients	Mean age 48 70% female	RA (definition NS)	To evaluate whether the quality of patient education could be improved by using written materials
Kumar(46) (2010) UK	15	Semi-structured qualitative focus group interviews	Rheumatology outpatients of Indian/Pakistani ethnic origin	Mean age 48 100% female	RA (definition NS)	To evaluate a face-to-face educational support session provided in patient's native language

Law(47) (2010) England	15	Moderated semi-structured qualitative focus group interviews comprising purposively sampled patients	Outpatients known to a hospital Rheumatology department	Age range 23-76 67% female	RA (ARA criteria)	To explore perceptions of patients regarding effects of exercise on joint health
Makelainen (48) (2009) England	173	Qualitative written questionnaire comprised of two open ended questions	Rheumatology outpatients from hospitals and health centres where nurses educate patients	Mean age 57 80% female	RA (definition NS)	To describe the content of patient education as portrayed and evaluated by RA patients
Meesters (50) (2009) Germany	165	Quantitative questionnaire – Dutch version of the Educational Needs Assessment Tool	Outpatients from a University hospital Rheumatology clinic	Mean age 68 88.5% female	RA (clinic diagnosis)	To describe the educational needs of Dutch patients with RA
Meesters (49) (2011) Holland	251	Quantitative postal questionnaire sent to a random sample of patients	Patients from an established registry of 1500 outpatients with RA	Mean age 60.5 72% female	RA (ACR criteria)	To measure patient perceived knowledge and information need regarding regional health care services and to identify preferred method of information provision
Neame(51) (2005) USA	344	Quantitative self reported questionnaire administered via mail	RA patients over age 18 registered on an electronic database to monitor DMARDs	Median age 65 67% female	RA (definition NS)	To measure the need for information about RA and desire to be involved in treatment decisions and examine factors associated with these preferences

Newman (52) (2009) England	34	Moderated semi-structured focus groups discussing information needs (n = 12) and a written questionnaire evaluating RA website	Outpatients from a hospital department of Rheumatology	Mean age 53 73% female	RA (definition NS)	To explore the views of users of an RA website to understand whether the website covers issues of value to people with RA and which resonate with their experiences
Nota(54) (2016) Netherlands	29	Qualitative semi-structured interviews	Rheumatology outpatients from two hospitals in the Netherlands	Mean age 56 66% female	RA (definition NS)	To gain insight into patient motives for wanting or not wanting to be involved in medical decision-making and factors that hinder or promote involvement
O'Hare(55) (2001) UK	18	Qualitative focus groups or semi-structured one on one interviews	Rheumatology ward inpatients and outpatient clinic	NS	RA (definition NS)	To explore perceptions of patients and health care professionals of the pharmaceutical care issues relating to RA
Pytel(56) (2012) Poland	270	Quantitative written questionnaire	Outpatients from a hospital outpatient clinic	Mean age 57 77% female	RA (definition NS)	To define source of patient knowledge about disease and role and tasks of health education
Salt(57) (2015) USA	10	Quantitative written survey	Outpatients of a single rheumatology clinic	Mean age 47.9 80% female	RA (ACR criteria)	To assess associations between patients' trust and demographic factors and to investigate associations between sources of information and patients' trust in their providers.

Schildman (58) (2008) Germany	22	Qualitative semi-structured in-depth interviews of purposively sampled patients	Outpatients from a University hospital clinic	Mean age 56.9 86% female	RA (ACR criteria)	To elicit patient perceptions and preferences regarding information and participation in treatment decision making
Ward(60) (2007) England	25	Qualitative structured one on one interviews	Outpatients from a rheumatology clinic	Median age 55 72% female	RA (ACR criteria)	To gain an understanding of what RA patients want and think they need from an outpatient clinic
<i>Ankylosing spondylitis (AS), psoriatic arthritis (PsA) and mixed inflammatory arthritis populations</i>						
Cooksey(35) (2012) Wales	211	Questionnaire containing closed and open questions administered via post or online	Pre-existing AS cohort recruited via GP, rheumatologist, member of National AS Society or physiotherapist	Mean age 57 19% female	AS (definition NS)	To investigate information utilization, sources and needs of people with AS
Dragoi(37) (2013) Austria	130	Quantitative survey including validated Education Needs Assessment Tool and Health Assessment Questionnaire	Outpatients from a Rheumatology outpatient clinic in Austria	Mean age 56 75% female	RA and PsA (ACR criteria)	To assess patient educational needs and its relationship with gender, disease activity and function
Dures(38) (2016) UK	19	Qualitative semi-structured interviews	Outpatients from a rheumatology clinic	Age range 27-75 74% female	RA and PsA (definition NS)	To identify in patients attending routine consultations aspects of the interaction that influenced collaboration and self-management

Hayden(43) (2015) UK	15	Qualitative semi-structured interviews	Rheumatology outpatient department	Age NS 11% female	Mixed inflammatory arthritis (definition NS)	To explore how both beliefs about necessity and concerns about methotrexate become established in patients with inflammatory arthritis and how patients use information in managing their beliefs and concerns.
Giacomelli (41) (2015) Italy	327 (RA) 214 (PsA) 200 (AS)	Quantitative written questionnaire using several validated health assessment tools	Rheumatology outpatient department	34% aged <45; 66% aged >45 58% female	RA, AS and PsA (defined by standard criteria)	To assess in patients with RA, AS and PsA their involvement in medical decisions, quality of life and unmet needs 15 years after the introduction of biological therapies in Italy.
Kjeken(45) (2006) Norway	1041 (RA) 152 (AS)	Written questionnaire with both quantitative and qualitative components	Patients from established Oslo RA and AS registers respectively (includes majority of affected patients in the region)	Mean age 60 74% female	RA (definition NS) and AS (New York Classification)	To examine levels of received information, involvement in medical decisions and satisfaction with care, to explore factors related to current involvement in medical decisions and to assess patients' unmet health care needs in relation to their disease
Nota(53)	31	Qualitative semi-	Rheumatology	Mean age 54	RA, AS and PsA	To explore what

(2015) Netherlands		structured face-to-face interviews	outpatient clinic	81% female	(definition NS)	considerations patients have when deciding about DMARDs and what information patients need to participate in the decision-making process
Van Eijk-Hustings (59) (2013) Holland	20	Qualitative moderated focus group interviews	Outpatients from three large rheumatology clinics	Mean age 57 75% female	RA and AS (clinical diagnosis)	To explore the needs and expectations with regards to rheumatology nursing care in patients with chronic inflammatory arthritis

Abbreviations: ARA – American Rheumatology Association; RA – rheumatoid arthritis; PsA – psoriatic arthritis; DMARD – disease modifying anti-rheumatic drug; NS – not specified; AS – ankylosing spondylitis; GP – general practitioner; ACR – American College of Rheumatology; PsA – psoriatic arthritis

Table 2: Quality assessments of quantitative studies as described by Hoy(31)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Berry 2008	-	-	+	+	+	+	-	+	-	+
Cunha-Miranda 2010	+	+	-	-	+	+	-	-	-	+
Dragoi 2013	-	-	-	-	+	+	+	+	-	+
Fraenkel 2001	-	+	+	-	+	-	-	+	-	+
Funahashi 2012	-	+	+	-	+	+	-	+	-	+
Giacomelli 2015	+	-	+	-	+	+	+	+	-	+
Meesters 2009	-	+	+	-	+	-	+	+	-	+
Meesters 2011	-	+	+	-	+	+	-	+	-	+
Neame 2005	-	-	+	-	+	-	-	+	-	+
Pytel 2012	-	+	-	-	+	-	-	+	-	+
Kjeken 2006	+	+	+	-	+	+	-	+	-	+
Salt 2015	-	-	-	+	+	+	+	+	-	+

Hoy et al tool(16) for assessing risk of bias in prevalence studies

1. Was the study's target population a close representation of the national population in relation to relevant variables?
2. Was the sampling frame a true or close representation of the target population?
3. Was some form of random selection used to select the sample, OR was a census undertaken?
4. Was the likelihood of nonresponse bias minimal?
5. Were data collected directly from the subjects (as opposed to a proxy)?
6. Was an acceptable case definition used in the study?
7. Was the study instrument that measured the parameter of interest shows to have validity and reliability?
8. Was the same mode of data collection used for all subjects?
9. Was the length of the shortest prevalence period for the parameter of interest appropriate?
10. Were the numerator(s) and denominator(s) for the parameter of interest appropriate?

Legend:

“+” = low risk of bias
“-” = high risk of bias

Table 3: Quality assessments of qualitative studies as per CASP tool(32)

Study	Domain 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Domain 7	Domain 8	Domain 9	Domain 10
Ackerman 2015	+	+	+	+	+	-	+	+	+	+
Barlow 2000	+	+	+	-	-	-	-	-	+	+
Dures 2016	+	+	+	+	+	+	+	+	+	+
Hardware 2015	+	+	+	+	+	-	+	+	+	+
Hayden 2015	+	+	+	-	+	-	+	+	+	+
Kaariainen 2010	+	+	+	-	-	-	+	-	+	+
Kumar 2010	+	+	+	+	+	+	+	+	+	+
Law 2010	+	+	+	+	+	-	+	+	+	+
Makelainen 2009	+	+	+	+	-	-	+	-	+	+
Newman 2005	+	+	+	-	-	-	+	-	+	+
Nota 2015	+	+	+	-	+	-	+	+	+	+
Nota 2016	+	+	+	+	+	-	+	+	+	+
O'Hare 2001	+	+	+	-	-	-	-	-	+	+
Schildman 2008	+	+	+	-	+	-	+	+	+	+
Ward 2007	+	+	+	-	-	-	+	+	+	+
Van Eijk-Hustings 2013	+	+	+	+	+	-	+	+	+	+
Cooksey 2012	+	+	+	+	-	-	+	+	+	+

CASP quality appraisal tool

1. Was there a clear statement of the aims of the research?
2. Is qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Legend:

“+” = low risk of bias

“-” = high risk of bias

Table 4: Patient perceived needs regarding health information

Study	Disease	Results
Reasons for seeking health information		
Barlow (2002)	RA	Patients want to be informed about prognosis for themselves but also for their families so they understand what might happen with their disease and treatment and allow for future planning
Dures (2016)	RA, PsA	Patients need to feel informed and knowledgeable to engage in their care
Kumar (2010)	RA	Patients desired information so they could learn to live with their disease have realistic future expectations
Newman (2009)	RA	Patients highlighted the importance of information for solving practical problems and maintaining control
Schildman (2008)	RA	Patients nominated a preference for information due to “interest in one’s own health” and for practical “use of information” e.g. being adequately educated to identify a symptom as a medication side effect
Demographic differences in health information needs		
Gender		
Ackerman (2015)	RA	There was a strong perception, particularly by arthritis consumer groups, that the needs of younger women with RA are not being well addressed
Cooksey (2012)	AS	Rates of information gathering higher in females than males
Dragoi (2013)	RA	Female patients expressed higher education needs than males in areas of movement (e.g. devices, ways to save energy, ways to lessen wear on joints) and feelings (e.g. dealing with stress or depression)
Fraenkel (2001)	RA	Women had stronger preference for information
Funahashi (2012)	RA	Being female associated with stronger preferences for disclosure of information
Meesters (2009)	RA	No association between gender and educational needs
Meesters (2011)	RA	No association between gender and information need regarding health services
Neame (2005)	RA	Need for information higher in women, especially if young and well educated
Age		
Cooksey (2012)	AS	Older patients more frequently reported being satisfied with level of information and not wanting any further Younger patients had higher preferences for seeking information online and lower for written information
Dragoi (2013)	RA	No difference in information needs based on age
Meesters (2009)	RA	Lower age associated with higher educational needs around support systems and managing pain and feelings
Meesters (2011)	RA	Higher age associated with lesser information need regarding health services

<i>Education, employment and socioeconomic status</i>		
Ackerman (2015)	RA	Patients with a health or research background had a clearer understanding of what information they needed
Dragoi (2013)	RA	No difference in information needs were identified based on educational background
Fraenkel (2001)	RA	In men higher education associated with stronger preference for information In women current employment associated with stronger preference for information
Funahashi (2012)	RA	Current employment and higher education level associated with stronger preference for information No relationship between household income and information preference
Makelainen (2009)	RA	Patients were dissatisfied with lack ongoing information or insufficient information
Meesters (2009)	RA	No association was seen between educational background and educational needs
Meesters (2011)	RA	No association was seen between educational background and need for information about health services
Pytel (2012)	RA	Interest in obtaining information on disease higher was in people with higher education
<i>Disease-related parameters</i>		
Dragoi (2013)	RA	Longer disease duration was associated with higher education needs in movement domain. There was a small correlation between disease activity and information need in domains of movement, feelings, treatment.
Funahashi (2012)	RA	No relationship was seen between perceived health status and information preference
Meesters (2009)	RA	Shorter disease duration was associated with higher educational needs in domain of “support systems”
Meesters (2011)	RA	Better physical function related to lower information needs regarding health services. There was no association of disease duration with information need regarding health services.
Neame (2005)	RA	In men prior DMARD adverse reactions or greater fatigue was associated with greater information seeking
<i>Patient perceived needs regarding the content of health information</i>		
<i>Diagnosis, pathophysiology, natural history and prognosis</i>		
Ackerman (2015)	RA	Women felt there was a dearth of consumer-focused information that addressed issues encountered by women with RA across the pregnancy continuum.
Barlow (2002)	RA	Patients wanted to be informed about prognosis including “worst scenario” possible
Cooksey (2012)	AS	Patients were less interested in purely factual information about disease course itself as they felt it would not change their outcome and was therefore of limited help
Cunha-Miranda (2010)	RA	Very few patients (<7%) wanted information on general information about what their disease is, causes or origins of the condition and disease progress
Giacomelli (2015)	RA, AS, PsA	60% of patients needed more information, especially about diagnosis, medication, exercises and how to improve performance of daily activities.

Hardware (2015)	RA	Some patients wanted information about how the disease would affect them in the future. Patients felt that most of the information should be given when first diagnosed.
Kjeken (2006)	RA, AS	Around half of patients who received no or some information about their diagnosis wanted more information; 23% who received much information still wanted more information
Kumar (2010)	RA	All participants agreed obtaining information about the disease itself was important
Meesters (2009)	RA	Patients rated information about the arthritis process as “very important”
Neame (2005)	RA	Over 90% agreed or strongly agreed about wanting information about their illness
Van Eijk-Hustings (2013)	RA, AS	Patients expressed need for information about their disease in general
<i>Pharmacological treatment – medication risks and benefits</i>		
Ackerman (2015)	RA	Patients wanted more information about drug toxicity and effects on their unborn or breast-fed baby
Barlow (2002)	RA	Patients desired information addressing drugs and side effects
Berry (2008)	RA	90.7% of patients wanted to be well informed about their medication. High importance ratings were given to information about drug doses, side effects, interactions, efficacy, medication type, evidence, risks of not taking, dosing, plan if missed or extra dose taken and alternatives to medication
Cunha-Miranda (2010)	RA	26.9% of patients wanted more information about therapies/treatment
Funahashi (2012)	RA	Most patients (70%) wanted to know about types and frequency of side effects and efficacy of a new treatment. 20% wanted to know percentage of responders and 35% were interested in monthly cost.
Hayden (2015)	Mixed	Written information gave patients practical information about the medication
Kumar (2010)	RA	All participants agreed on importance of obtaining information about the rationale of drug treatment, potential risks of therapy and other management approaches
Meesters (2009)	RA	Information about treatment from health professionals was rated “very important”
Neame (2005)	RA	>90% agreed about wanting information about treatment including side effects and alternatives
Nota (2015)	RA, AS, PsA	Patients stated that they often only received information about one treatment option, and would like more information about other available treatments.
Schildman (2008)	RA	Most patients (20/22) wanted to be informed about possible side effects of a treatment. All patients desired a treatment recommendation by their physician.
Van Eijk-Hustings (2013)	RA, AS	Patients expressed a need for information about treatment and potential side effects

<i>Amount of information</i>		
Barlow (2002)	RA	Some patients were wary of “too much” information about side effects and other negative information
Cunha-Miranda (2010)	RA	Although 68.2% of patients considered themselves well informed about their disease, 78% expressed that they still had unmet additional information needs
Dragoi (2013)	RA	70% of surveyed patients were interested in receiving education; 57% wanted to know “everything”, 18.5% “a lot of things”, 18.5% “some things” and 4.6% “none”
Fraenkel (2001)	RA	89% strongly agreed (and 8% agreed) with statements reflecting preference for full information disclosure in regards to treatment related risks and therapeutic options
Hayden (2015)	Mixed	Information about medications made patients worry due to a perceived focus on medication side-effects.
Giacomelli (2015)	RA, AS, PsA	Only one third of patients were satisfied with the amount of information provided. Of the biologic-treated patients, 51% of patients perceived the amount of information received to be adequate.
Kjeken (2006)	RA, AS	Many patients who had received much information about diagnosis, exercises and improved performance still had unmet information needs in these areas
Makelainen (2009)	RA	Patients were dissatisfied with lack ongoing information or insufficient information
Nota (2015)	RA, AS, PsA	The need for information varied highly
O’Hare (2001)	RA	Patients described experience of “over education” by healthcare professionals which could lead to anxiety
Schildman (2008)	RA	Minority (2/22) desired minimal information due to concern it may create anxiety
<i>Exercise and physical therapy</i>		
Barlow (2002)	RA	Patients expressed interest in information about the aims of exercises and requested appropriate instructions on how to carry exercises out
Kjeken (2006)	RA, AS	69% of patients who received no, 55% who received some and 17% who received much information about exercises wanted more information
Law (2010)	RA	Patients expressed need for more specific exercise instructions e.g. type of exercise, amount and information about potential harm to joints with exercise
Meesters (2009)	RA	Patients considered education about movement and exercise “very important”
Meesters (2011)	RA	Around one third of patients indicated a need for information about accessibility and content of services related to physical therapy (exercise therapy, physiotherapy)
Van Eijk-Hustings (2013)	RA, AS	Patients identified need for education about assistive devices

<i>Social and self management issues</i>		
Ackerman (2015)	RA	Patients wanted more practical strategies to assist with daily challenges. Women wanted more RA-related information to be available for families and workplaces.
Barlow (2002)	RA	Patients expressed a need for information about emotional impact and coping with disease/flare and for information about self management (e.g. exercise, use of aids) and employment issues
Cunha-Miranda (2010)	RA	17.5% of patients wanted information on social support and 16.6% of patients desired information on how to improve their symptoms and live better in everyday life
Cooksey (2012)	AS	Patients favoured practical information and self-help guidance
Giacomelli (2015)	RA, AS, PsA	Patients wished for more information about how to improve performance of daily activities.
Hardware (2015)	RA	Doctors and nurses were seen to provide useful information about accessing help and social support. Having access to a telephone helpline service was reassuring to patients.
Kaariainen (2010)	RA	Patients requested more education about how to cope with their disease in everyday life with information targeted to their specific needs and issues
Kjeken (2006)	RA, AS	48% of patients who received no, 44% who received some and 11% who received much information about improving performance in daily activities wanted more
Makelainen (2009)	RA	Patients wanted information focused on emotional wellbeing or psychosocial issues
Meesters (2009)	RA	Patients rated education about emotions “fairly important”, information about support systems between “fairly” and “a little” important and information about self-help between “a little” and “very” important
Meesters (2011)	RA	Around one third of patients indicated a need for information about content and accessibility of patient education and self management services
Van Eijk-Hustings (2013)	RA, AS	Patients identified a need for education about self management strategies e.g. dealing with limitations and how to communicate to others about their limitations
<i>Pain management</i>		
Barlow (2002)	RA	Interest shown in knowing more about pain management and treatment of flares
Meesters (2009)	RA	Patients attributed moderate importance to educational needs about managing pain
<i>Healthcare services</i>		
Ackerman (2015)	RA	Women wanted more information about access to physical and emotional support services.
Meesters (2011)	RA	In regards to healthcare services (medical, allied health, psychosocial), 69% of patients reported an information need about content and 61% about accessibility

Van Eijk-Hustings (2013)	RA, AS	Patients expressed a need for information about healthcare facilities
Current research information		
Cooksey (2012)	AS	65% of patients wanted summaries of the latest research in AS
Cunha-Miranda (2010)	RA	17.5% wanted information on new scientific developments in managing their disease but very few (<7%) wanted information about specific studies
Miscellaneous		
Ackerman (2015)	RA	Patients wanted more information to be made available for family, friends and colleagues, to improve their understanding of the challenges faced and to garner support.
Cooksey (2012)	AS	43% of patients wanted stories and experiences from other patients with AS and 27% of patients wanted information about local events related to their disease
Hardware (2015)	RA	Integrating varied sources of information from health professionals, family and friends enabled patients to make decisions and helped them cope with their disease
Preferred information delivery and communication methods		
General preferences		
Ackerman (2015)	RA	The majority of women reported that their main source of information was their rheumatologist. Some women preferred information packs from health professionals or arthritis consumer organisations. Patients wanted the material to be reviewed regularly to ensure relevance.
Cunha-Miranda (2010)	RA	Preferred sources about disease were: rheumatologist (67.7%), GP (31.4%), internet (17%), nurse (9.9%), other patients (7.2%), talks (2.7%), media (2.7%), patient association (1.3%), Rheumatology institute (2.7%), pharmacy (1.3%), books (1.3%). Preferred sources about treatment were: rheumatologist (85.2%), GP (25.1%), internet (10.3%), nurse (6.3%), other patients (1.3%), talks (2.7%), media (6.3%), patient association (0%), Rheumatology institute (1.3%), pharmacy (1.3%), books (0%)
Giacomelli (2015)	RA, AS, PsA	The other main sources of information used by patients were the Internet, television and newspapers.
Hayden (2015)	Mixed	Patients described how information about methotrexate was given at the same time as the diagnosis, and often the shock of the diagnosis contributed to difficulties absorbing information. Patients report seeking information from the Internet, however they felt that it did little to allay concerns.
Meesters (2011)	RA	Preferred sources about health services: written information (79%), internet or email (21%), personal contact with professional (12%), telephone helpline (6%)

Nota (2015)	RA, AS, PsA	Patients obtain information from many sources. Many patients were satisfied with the information provided by health professionals, however, they felt that the difference between the medications was not clear. Other patients found it difficult to comprehend contradictory information from different caregivers. Some patients used the Internet, and found this mostly satisfying as it confirmed the information provided by the doctor. Some patients received information from pharmaceutical companies particularly relating to biologic DMARDs
Salt (2015)	RA	The most widely used sources of information were handouts from their provider (79%), the Internet (64%), another provider (57%). The least frequently used sources were mailed brochures (14%), television (17%) and magazines (24%). Patients often reported using multiple sources of information.
<i>One-to-one delivery of information</i>		
Barlow (2002)	RA	One-to-one delivery of information was the preferred format for disease based information, preferably provided by rheumatology team at outpatient clinic. The preferred format for information about emotional and quality of life issues was provided by health professional or someone else with arthritis
Kaariainen (2010)	RA	Patients valued face-to-face interventions, in particular the opportunity for two way interaction and to ask questions and express feelings
Kumar (2010)	RA	Education via trained volunteer in native language considered valuable for patients of non-English speaking backgrounds in terms of communication and having someone with a personal understanding of their disease
Ward (2007)	RA	Patients wanted to be given clear explanations by their practitioners
<i>Written information</i>		
Barlow (2002)	RA	Leaflets were considered useful “aids to memory” for information e.g. drug names, exercise information or instructions, important contacts. Written information was identified as a way to disseminate coping strategies other patients found useful but was thought to be too general to meet specific needs. Patients suggested information packs people could “dip in and out” according to need.
Cooksey (2012)	AS	Patients suggested more written information to improve patient information. 95% of patients would like to receive regular or occasional newsletter about AS.
Dures (2016)	RA, PsA	Patients want visual materials and written records to aid communication and understanding
Hayden (2015)	Mixed	Patients felt that written information about medications lacked detail of how the drug worked and specifically the nature of benefits that they could reasonably expect.
Ward (2007)	RA	Patients wanted additional information to be provided in written form

<i>Electronic or audio-visual information</i>		
Ackerman (2015)	RA	Patients expressed a strong preference for electronic information, particularly those in rural settings.
Barlow (2002)	RA	Videos were considered advantageous for sharing information (e.g. how families have coped), how to use aids/devices and visual reminder for safe exercises while computers were not considered suitable for communication of information or advice
Cooksey (2012)	AS	Barriers to using the internet for information included not trusting information on the internet and preferring other sources
Newman (2009)	RA	Internet was seen as a useful resource for rheumatology information however there were concerns about quality of information, sheer volume of material and difficulty locating the specific information needed
Kumar (2010)	RA	A bilingual educational CD was seen as a useful tool for patients of non-English speaking backgrounds, with audio format seen to be more accessible than written and useful to share with family/friends
<i>Group education</i>		
Barlow (2002)	RA	Group education was seen to be an acceptable format for information about emotional and quality of life issues, disease self-management techniques, exercise and relationships. It was thought to be a good forum for sharing ideas and problem solving and group sessions were seen to provide “motivation”, “fun element” and forum for “socialising”. There was a preference for self-made local groups due to distance, timing, travel
Cooksey (2012)	AS	Patients identified AS groups and advice from others as a potentially useful source of information/support
Newman (2009)	RA	Patients appreciated the patient perspective of information with “insider knowledge” seen as valuable
<i>Techniques and tone</i>		
Barlow (2002)	RA	Patients wanted a “positive approach” and were wary of receiving too much negative information. Patients were more interested in information specific to their own disease, as “it is different for everyone”
Cooksey (2012)	AS	Some patients felt the tone of information was too negative “all doom and gloom”
Dures (2016)	RA, PsA	Patients wanted open, patient-centred communication styles
Kaariainen (2010)	RA	Patients wanted information targeted to their specific needs
Makelainen (2009)	RA	Patients valued clear explanations using understandable terminology, adequate time, feeling comfortable Patients were dissatisfied with information not tailored to their needs
Newman (2009)	RA	Patients expressed need for “positive” information and inclusion of positive experiences and attitudes
Van Eijk-Hustings (2013)	RA, AS	Patients wanted information to be appropriate, tailored and timely

Barriers to meeting health information needs		
Ackerman (2015)	RA	Patients were frustrated at receiving inconsistent advice and the lack of knowledge regarding RA and its management among nurses, medical practitioners and pharmacists.
Barlow (2002)	RA	Patients were reluctant to use an available phone helpline during a flare as they knew the clinic was busy and did not want to be a “nuisance”
Cooksey (2012)	AS	Patients felt improved information delivery could be achieved by improving GP knowledge and that limited access to specialist clinics / health professionals was a barrier to obtaining desired information
Kumar (2010)	RA	Patients of non-English speaking background identified language as a barrier in obtaining information with difficulty communicating via interpreters, lack of time in clinic to answer questions and the majority of available written information being in English
Law (2010)	RA	In regards to information about exercise patients felt health professionals showed a lack of knowledge about specifics of exercise prescription
Newman (2009)	RA	Patients reported that the complex and changing nature of RA meant an unpredictable need for information throughout course of disease

