

Review Article

Patient-reported quality of care in anthroposophic and integrative medicine: A scoping review

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ABSTRACT

Objective: To investigate how, and to what extent, patient-reported quality of care is measured in Anthroposophic and Integrative Medicine (AM/IM).

Methods: Scoping review of evaluation studies of patient-reported quality of care and development studies of PREMs and/or PROMs in AM/IM, using five stages of Arksey's methodological framework. **Search strategy:** Literature search in twelve relevant databases. **Data extraction:** Basic information, added categories: Focus; PREMs/PROMs; Evaluation measures; Patient involvement; Use of results.

Results: Sixty-four included studies: 30 quantitative, 20 qualitative and 14 mixed-methods studies. Quantitative studies showed a wide variety of instruments and qualitative studies showed a meaningful list of evaluation themes. Most prevalent themes: Agency & Empowerment; Patient-provider relationship; Perceived effectiveness; Coping & Psychological functioning; Inner awareness; Meaning; and General wellbeing. Seven studies report concrete, coherent, patient-derived evaluation measures with emphasis on PROMs and/or PREMs.

Conclusion: Patient-reported quality of care was not measured in a standardised way. Knowledge gap: in general, quantitative studies lack patient-derived measures and qualitative studies lack development of concrete evaluation measures. Many AM/IM evaluation aspects connect with patient-centred care.

Practice implication: The international field of AM/IM would benefit from the development of a core set of validated PROMs and PREMs to further enhance its scientific underpinning.

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1. Introduction

Anthroposophic and Integrative Medicine (AM/IM) are promising forms of healthcare that have increased their scientific underpinnings enormously in the past ten years [1–11].

The American Board of Integrative Medicine (ABOIM) and the Consortium of Academic Health Centres for Integrative Medicine (CAHCIM) have defined Integrative Medicine (IM) as “*the practice of medicine that reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic approaches, healthcare professionals, and disciplines to achieve optimal health and healing.*” [12]

Hence, IM practices a combination of conventional biomedical-based medicine and Traditional and Complementary Medicine (T&CM) [2]. Conventional bio-medical based medicine has been developed in Western countries and is rooted in the natural sciences [13]. Traditional medicine is “*the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness*” [14]. Complementary medicine refers to “*a broad set of healthcare practices that are not part of that country's own tradition or conventional medicine and are not fully integrated into the dominant health-care system*” [14]. Because the two are used interchangeably the WHO has merged them into the term T&CM [15]. The increasing use of T&CM and need for integration with conventional medicine is an important drive behind the development of IM, supported by the WHO [2,15–17].

A form of IM, Anthroposophic Medicine (AM) has originated in Europe in the 1920s and is currently practiced by medical, paramedical and therapeutic practitioners in 80 countries worldwide [18]. Aspects of AM treatment are an individualised approach, both preventive and curative health promotion, medicinal use of substances and non-medication therapies [1,18]. AM has an important strength in the sense that it has both developed from the roots of the natural sciences in Europe - the same roots as conventional biomedical-based medicine has developed from [13] and has integrated biomedical-based medicine and complementary therapies from the start of its development [2]. This means that AM not only has practiced IM for over 90 years, also the integrative character is deeply connected with AM's identity [2].

In the context of the evidence-based medicine development, research on IM has necessarily focused on biomedical quality and clinical evidence, regarding efficacy, (cost-) effectiveness and safety [1,5,7,19–25]. However, whereas clinical research in AM/IM has increased and served the important purpose of establishing evidence on safety and effects of treatment, health services research is under-developed [19] and would be a legitimate next step in the scientific development of AM/IM.

Health services research is defined as the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviours affect access to healthcare, the quality and cost of healthcare, and ultimately our health and well-being [26]. Part of this field is measuring patient-reported quality of care, which has become essential in evaluating healthcare performance [27–29].

Within conventional medicine specific methodologies have been developed to evaluate patient-reported quality of care, in which a division is made between process aspects and outcomes aspects of care [27,30–32]. On the one hand, process aspects are measured using Patient Reported Experience Measures (PREMs), for example, communication, patient-provider relationship, accessibility, tailored care and cooperation between care providers [33]. On the other hand, outcome aspects – general and specific – are measured using Patient Reported Outcomes Measures (PROMs) [30,32,34]. Examples of disease-specific outcomes are bodily function after surgery, and reduction or recovery of specific symptoms or illnesses. General outcomes are usually measured with *Quality of Life* instruments, such as EQ-5D and SF-12 or SF-36 [35–37].

Another important reason to measure patient-reported quality of care in AM/IM is the fact that both IM and AM espouse patient-centred or individualised care as a leading principle [2,7,17,35,38], which is highly valued by patients [16]. As such, AM/IM seem to have a potential to contribute to further develop and enhance the delivery of patient-centred care [7,17,35]. Measuring patient-reported quality of care in AM/IM addresses this principle.

Because it is important for AM/IM to further develop health services research in general, and measuring patient-reported quality of care specifically, it is necessary to map and scope the body of knowledge that *has* been built so far and to identify the precise extent of the knowledge gap. Therefore, to investigate this potential knowledge gap the aim of this research is to perform a scoping review. The research question is: how and to what extent is patient-reported quality of care measured in health services research in the field of AM/IM?

2. Methods

The aim of a scoping review is to map and present an overview of the body of literature on a specific topic area [39,40]. The intent is to articulate what is known about key concepts, both in-depth as well as in a broad sense, by including a larger range of studies than systematic reviews [40]. A scoping review provides a descriptive overview of the included studies without critically appraising the methodology of individual studies or synthesising evidence from different studies. An additional reason for conducting a scoping review is to identify research and knowledge gaps within the topic area [39,40].

Arksey's methodological framework proposed an iterative five-stage process [40]:

- Stage 1: identifying the research question
- Stage 2: identifying relevant studies (search strategy)
- Stage 3: study selection
- Stage 4: charting the data (data extraction)
- Stage 5: collating, summarising and reporting the results

The aim of these stages is to create an underpinning with equal extent of rigorousness and transparency as with systematic reviews [40]. Following the recommendation of Arksey et al. (2005) and Levac et al. (2010) this section provides a description of how the stages were addressed. In addition, to enhance the quality of this review the PRISMA statement for systematic reviews was followed where possible.

2.1. Stage 1: Identifying the research question

The research question is:

How, and to what extent, is patient-reported quality of care measured in health services research within the field of IM and AM?

Sub-questions:

- 1) How many studies exist in this field?
- 2) Which methods are used?
- 3) What aspects are measured?
- 4) In which way are patients involved in defining which aspects to measure?
- 5) What purposes are results used for?
- 6) Is patient-reported quality of care measured in a standardised way?
- 7) Are measures underpinned with theoretical concepts of IM?

This research question implies that patient-reported outcomes measured in clinical trials are excluded from this scoping review. The focus is on so-called real world data [41]. The authors investigated openly which instruments and methods were used to evaluate patient-reported quality of care, without critically appraising whether the instruments at issue were initially made for this purpose. In addition, patient-reported quality of care was addressed in the form of *retrospective evaluation* as opposed to prospective motives for and expectations of use of care.

2.2. Stage 2: Identifying relevant studies (search strategy)

The electronic database search took place on February 24th 2017 and was conducted with a search engine that combined several relevant databases (See [Box 1](#)). The search terms (See [Box 1](#)) were determined after an initial literature- and database search, in consensus between the authors, and with advice from a librarian of

UAS Leiden. Search terms had to be present in title, abstract and/or subject terms of the publication. No time frame was set.

In addition to a database search, Arksey et al. (2005) and Levac et al. (2010) also recommend identifying relevant literature by means of checking reference lists, hand searching of key journals, and existing networks. A pre-investigation of existing relevant research within the authors' network showed little attention for the combination of AM/IM and evaluating patient-reported quality of care [7,42]. At the same time, within the authors' extensive network on evaluating quality of care and health services research there is little expertise on AM/IM. Potential key journals were pre-explored. This exploration showed a similar picture: within journals about health services research, there were few search results on AM/IM, and within journals about AM/IM few articles on patient-reported quality of care studies. Considering the above and the large number of databases included in the search, the authors chose to conduct the scoping review using only electronic database sources.

2.3. Stage 3: Study selection

2.3.1. Inclusion criteria

The included studies met the following criteria:

- A description or analyses of the *evaluation* of quality of actual delivered care as reported by patients in AM/IM care, based on the definition of IM
- Both qualitative and/or quantitative
- Used or developed measurement instruments, serving as PREMs, PROMs or other evaluation instruments
- Languages: English, German, Dutch and French

2.3.2. Exclusion criteria

Studies were excluded based on the following criteria:

- Theoretical non-empirical studies and/or essays about aspects of care considered to be of value regarding the quality of care
- Patients' motives for and expectation of the use of AM/IM
- Other languages
- Unavailability of both abstract and full text article
- Clinical trials and other studies focussing on clinical effectiveness of interventions [32,43]
- Lack of relevance otherwise (for example; no IM, no patients, organizational implementation, no quality of care)

2.3.3. Definitive selection

The selection of studies was initially based on the titles and abstracts. When the abstract did not provide enough information

Box 1. Details on search strategy

Databases in the search engine:

Academic Search Premier (EBSCOhost), BioMed Central, CINAHL with Full Text (EBSCOhost), Cochrane Library, EBSCO Open Access Journals, MEDLINE with Full Text (EBSCOhost), NARCIS - National Academic Research and Collaborations Information System, Psychology & Behavioral Sciences Collection (EBSCOhost), PsycINFO (EBSCOhost), PubMed Central (PMC), ScienceDirect and SpringerLink.

The search was built as follows:

("patient experiences" OR "patient reported outcomes" OR "patient satisfaction" OR "patient perspectives" OR "patient evaluation" OR "instrument development" OR "patients' experiences" OR "patients' perspectives" OR "patient relevant outcomes") AND (anthropos* OR "anthroposophic healthcare" OR "anthroposophic health care" OR "anthroposophic medicine" OR "integrative care" OR "anthroposophic care" OR "integrative health" OR "integrative medicine" OR "integrative health care" OR "integrative healthcare")

the full-text was assessed. Two authors assessed all studies independently, based on clear inclusion and exclusion criteria, agreed among all authors. Uncertainties were discussed and consensus was formed.

2.4. Stage 4: Charting the data (data extraction)

The following information was collected: first author; year of publication; journal; country; setting; aim; focus within the study; population and illness; number of participants; method; design; involvement of PREMs, PROMs or patient satisfaction; evaluation measures or aspects; patient involvement; use of results.

A number of categories required the use of iterative process, because often the information was not explicitly reported within the selected studies. Those categories were: design; involvement of PREMs, PROMs or patient satisfaction; evaluation measures or aspects; patient involvement; and use of results.

Two categories needed extra literature to chart its data. For defining the correct quasi-experimental research designs Harris et al. [2006] was followed. For categorising the ways and extent of patient involvement in the process of measuring outcomes and experiences of care the classification developed by Wiering et al. [44] was followed. These categories are, in order of increasing involvement: 1. Using patients for testing comprehensibility of measures, 2. Involving patients in item development, and 3. Involving patients in establishing outcome measures. A random sample of 20 studies was assessed in duplicate independently to develop inter-researcher validity. Contradictions and doubts were discussed to achieve consensus.

2.5. Stage 5: Collating, summarising and reporting the results

In stage five the end product of the scoping review was developed. It is a narrative presentation that synthesises the research and applies meaning to the results. Following the recommendation of Levac et al. [39] three steps were taken in reporting this stage: analysing the data (collating and summarising), reporting results, and applying meaning to the results. Analysing the data involved both a descriptive numerical summary (Table 1 and 2) and a thematic analysis (Table 3). The numerical summary included all the information categories from the previous phase. Conducting the thematic analysis researchers kept to the phrasing and meaning of the items in the included studies. Only when items were obviously about the same theme, they were clustered. Starting from the numerical analysis researchers looked for meaningful patterns in the content of the publications. In addition, gaps of knowledge were identified.

3. Results

3.1. Search flow

The flow chart is shown in Fig. 1. It shows 381 identified studies, of which 188 duplicates were removed. In total, 64 studies were included in the review.

3.2. General study characteristics

The numerical summaries of the study characteristics are shown in Table 1. The complete results of the data extraction are shown in appendix 1. The descriptions below follow the headlines of the table. The included studies were published between 2002 and 2016. Most studies were conducted in the USA ($n=26$). Regarding settings most studies took place in IM clinics ($n=15$) and academic centres ($n=11$), followed by primary care ($n=9$) and

general hospitals ($n=8$). The diseases concerned varied enormously.

3.3. Methods and design characteristics

Forty-four studies used quantitative methods, – solely quantitative ($n=30$); mixed methods ($n=14$) – most of them having cross-sectional ($n=15$), cohort ($n=11$) and quasi-experimental ($n=10$) study designs. Thirty-four studies used qualitative methods – qualitative ($n=20$) and mixed methods ($n=14$). Twenty studies used interviews and/or focus group designs. Thirty-two studies measured patient-reported quality as main purpose of the study, and seven studies were instrument development studies.

3.4. Patient involvement

To categorise patient involvement, categories (1–3) of Wiering et al. [44] were used.

In 20 studies these categories were applicable: one study used patients for testing comprehensibility, in 15 studies patients had a voice in the item development phase, and in four studies patients were involved in establishing outcome measures. However, in many of included studies patient involvement was deemed lower than category one. Therefore, two categories of patient involvement were added. We distinguished between respondents of surveys and respondents of interviews; the latter was considered as a higher level of involvement, because in interviews patients have usually more influence in the way they answer questions than in surveys. Details are shown in Table 1. In almost half of the included studies patients' involvement was limited to being respondents in a survey. In most qualitative studies patient involvement was on the level of item development or higher. The mixed-method studies varied the most regarding their level of patient-involvement of each study. Hence, these findings indicate a limited degree of patient-involvement.

3.5. Use of results

The results of the studies are used for various purposes. Most study results are used for further instrument development, further research, care implementation and advocacy of AM/IM. Quality improvement, service- and outcome evaluation, important purposes associated with PREMs and PROMs, were less mentioned. Details are shown in Table 1.

3.6. Evaluation measures

Table 2 shows which existing questionnaires are used in the quantitative and mixed methods studies. Many different instruments were used: 22 as a PROM and twelve as a PREM. Although several questionnaires are well known and validated, the authors cannot confirm the validity of all of these questionnaires. Also, in general, the items of these instruments were not explicitly mentioned in the studies.

Contrary to the use of pre-structured questionnaires, 22 studies composed a variety of quantitative evaluation measures themselves. The variety of measures differed greatly within as well as between the quantitative studies. Although some standard themes are recognisable when comparing these studies – for example, effectiveness, satisfaction or relationship with practitioner, quality of life and likelihood to recommend – the specific sets of measures that are used within a single study often lack reasoning for the choices made and come across as somewhat arbitrary.

Table 3 provides an overview of evaluation categories that were generated and/or assessed in the qualitative studies and qualitative parts of the mixed method studies. The themes emerged from the

Table 1
Study Characteristics – numerical summaries.

Characteristic	Amount of studies	Characteristic	Amount of studies	Characteristic	Amount of studies
A. Year of publication		D. Illnesses		H. PREMs and PROMs	
2002	1	Various/Non-Specified	27	PREM	3
2003	2	Cancer	10	PROM	16
2004	3	Chronic conditions	6	PREM and PROM	7
2005	5	Mental problems	4	None	38
2007	3	Pain	4	Total	64
2008	5	Osteoarthritis	2	I. Patient involvement	
2010	6	Spinal problems	2	Respondents Survey	31
2011	2	Surgical patients	2	Respondents Interviews	10
2012	10	Primary dystonia	1	Testing comprehensibility	1
2013	4	HIV	1	Item development	15
2014	11	Interstitial Cystitis	1	Establishing outcome measures	4
2015	5	Cardiac conditions	1	Unknown	3
2016	7	Parkinson's' disease	1	Total	64
Total	64	Respiratory and ear complaints	1	J. Use of results	
		Stress related symptoms	1	Further research	15
		Total	64	Instrument development	15
B. Country		E. Methods		Care implementation/innovation	10
USA	26	Quantitative	30	Advocating IM	10
Australia	5	Qualitative	20	Quality improvement	10
Sweden	5	Mixed methods	14	Care/service evaluation	7
Canada	4	Total	64	Comparing IM with CON	5
Germany	4	F. Design		Outcome evaluation	6
The Netherlands	4	Interviews and/or focus groups/ narratives	20	Underpinning effectiveness	2
UK	4	Cross-sectional	15	Improving patient satisfaction	1
Switzerland	2	Cohort study	11	Addressing patients' voice	1
India	2	Quasi-experimental	10		
Korea	2	Literature study	3		
Israel	2	Case study	2		
Thailand	1	Interrupted time series	1		
Saudi Arabia	1	Systematic review	1		
Hong Kong	1	ROM	1		
Mixed	1	Total	64		
Total	64	G. Focus of patient-reported quality			
C. Setting		Main purpose	32		
IM clinic	15	Part of larger study	25		
Academic centres	11	Instrument development study	7		
Primary care	9	Total	64		
General hospital	8				
Cancer care otherwise	5				
Community healthcare	4				
Specialised/individual practitioners	4				
Mental healthcare	3				
Teaching hospitals/ clinics	2				
Other	3				
Total	64				

items that were described in the studies. During the analysis, the researchers stayed as close as possible to the meaning of the items, resulting in a long list of categories. Seven evaluation categories were most prevalent in these studies and had a prevalence of ten or more items in the studies all together. These were (number of items): Agency & Empowerment (23); Patient-provider relationship (21); Perceived effectiveness (18); Coping & Psychological functioning (14); Inner awareness (14); Meaning (11); and General wellbeing (10). Two other categories were also similarly prevalent in the studies. However, one category contained outcome- and experiences measures that were quite vague and lacked specification (18), for example “health outcomes”. The other category contained “patient satisfaction” without specifying the precise meaning of it (10). Therefore, these two categories show low content value.

In addition, in none of the studies an explicit coherence was made between the evaluation measures and the theoretical base of IM.

3.7. PREM and PROM assessment

Twenty-seven studies focused on PREMs, PROMs or both, and seven of those had a patient-involvement level of minimal “item development”. (See Table 4) Three of them are instrument development studies with a patient-involvement level on “establishing outcome measures” (Hunter 2014; Eton et al. 2005; and Koster et al. 2014). The other four studies (Keshet et al. 2015; Koster et al. 2016; Mulkins et al. 2003; and Verhoef et al. 2005) report a thorough qualitative phase of item development on the way to PROM and/or PREM construction. All of these seven studies report concrete and/or coherent evaluation measures.

Table 2
Instruments used for evaluation of AM/IM care.

PROM questionnaires	PREM questionnaires
SF-12 (4x)	Integrative Medicine Patient Satisfaction Scale (IMPSS)
SF-36 (4x)	Patient Satisfaction Index (PSI)
Patient Care Monitor	EUROPEP (2x)
Integrative Medicine Outcome Scale (IMOS)	CQ-Index General Practice
Life Satisfaction Questionnaire (LSQ)	CQ-Index Anthroposophic Medicine
PROMIS-Pain Interference 6b	Patient Enablement Index
EQ-5D-5L	Patient satisfaction score (scale 1-100);
Edmonton Symptom Assessment Scale (ESAS);	Patient Satisfaction scores (rating 0-10)
Patient Reported Outcomes Measurement Information System Global Health (PROMIS-10)	Columbia Health Medical Services Patient Satisfaction Survey
Memorial Symptoms Assessment Scale (MSAS)	Picker Inpatient Questionnaire
Measure Yourself Concerns and Wellbeing Questionnaire (2x)	Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)
Berg Balance Scale (BBS)	Consultation and Relational Empathy Measure
Parkinson's Disease Questionnaire (PDQ-39)	
Arizona Integrative Outcome Scale (AIOS)	
Patient Activation Measure	
Perceived Stress Scale-4	
PROMIS-29	
Holistic Health Questionnaire	
Integrative Medicine Patient Satisfaction Tool	
Picker Inpatient Questionnaire (2x)	
Arthritis Health Assessment Questionnaire	
QOL-scale	

4. Discussion

4.1. Discussion

In this study the authors performed a scoping review on how and to what extent patient-reported quality of care is measured in health services research within the field of AM/IM, in order to

Table 3
Evaluation aspects from qualitative studies.

Domain	Number of items
Agency and empowerment	23
Patient-provider relationship	21
Perceived effectiveness (symptoms, pain)	18
Coping and psychological functioning	14
Inner awareness	14
Meaning	11
General patient satisfaction	10
General wellbeing	10
Transformation/turning point/new perspectives	8
Program evaluation	7
Quality of life	6
Holistic philosophy	6
Skills and knowledge practitioner	5
Support	5
Clinic's atmosphere	5
Feeling connected	4
Integration of care	4
Team collaboration	4
Accessibility	4
Energy/vitality	3
Social relationships	3
Functioning	3
Patient-centred care	3
Relaxation	3
Stress and anxiety	3
Information	2
Natural healing	2
Physiological indicators	2
Side effects	2
Treatment options	2
Additional treatment costs	1
Safety	1
Unmet needs	1
Other/non-specified aspects	18

identify a potential knowledge gap regarding the assessment of patient-reported quality of care within this field. The sub-questions were: 1) How many studies exist in this field? 2) Which methods are used? 3) What aspects are measured? 4) In which way are patients involved in defining which aspects to measure? 5) What purposes are results used for? 6) Is patient-reported quality of care measured in a standardised way? And 7) Are measures underpinned with theoretical concepts of IM? In total, 64 studies were included; these were published between 2002 and 2016. Thirty quantitative, 20 qualitative and 14 mixed method studies were conducted. Patient-reported quality of care was measured both as main purpose of studies and as part of larger studies. The results of the studies are used for various purposes.

A wide variety of quantitative instruments were used. A reason for this could be the variety of care that is evaluated. If this explanation would apply one would expect that similar aspects would be measured in the same way, which is, however, not the case. Consensus on a standard instrument that measures different aspects of IM seems to be lacking. For example, although the Patient Activation Measure was initially not designed to be a PROM [45], one study (Dusek et al. 2016) used the instruments for this purpose. Also the Picker Inpatient Questionnaire was used both as PREM and as PROM.

Within the qualitative methods, seven evaluation themes were most prevalent: Agency & Empowerment; Patient-provider relationship; Perceived effectiveness; Coping & Psychological functioning; Inner awareness; Meaning; and General wellbeing. Because most qualitative studies investigated aspects that were relevant for patients and had a patient-involvement level [44] of *item development* or higher the wide prevalence of these themes indicates that they are regarded to be the most important from patients' perspective. Two of them Agency & Empowerment and Patient-provider relationship are relatively new regarding measuring outcomes of care [35], and the amount of research that focuses on understanding their mechanisms is increasing [46–49].

In both qualitative and quantitative studies "patient satisfaction" was often used as an evaluation measure. In these cases "patient satisfaction" was not further specified or operationalised and left to interpretation of the respondent. This disputed its validity. The original idea behind the development of *experience*

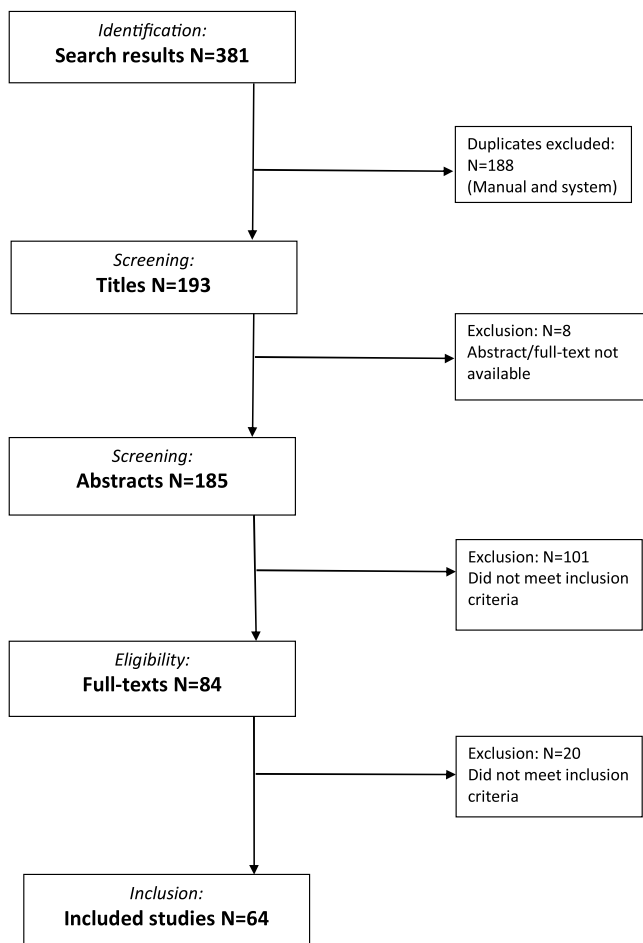


Fig. 1. Flow chart.

measures in the first decade of this century was to enhance the way of evaluating patient perspectives at that time by replacing arbitrary measures of “*patient satisfaction*” by measures of *concrete experiences* with received care [29]. This review demonstrates that in IM the awareness for this development could be improved.

The degree of patient involvement was – in general – quite low. The assessment of patient involvement was limited by the fact that the studies did not give an account of patient-involvement in the development of the existing pre-structured questionnaires. However, the shortcoming correlates with findings of Wiering et al. [44] in conventional medicine. Apart from positive exceptions, the general degree of patient involvement in developing PROMs is lower than desirable and lower than would be expected based on the increasing importance of patients perspectives in the evaluation of healthcare [44]. The current study indicates that patient involvement in IM is even lower than in conventional medicine. This is particularly striking, because of IM’s leading principle of patient-centeredness: a focus on optimal health for the individual patient and the reaffirmation of the patient-provider relationship [12] in both of which the patient has an active role. [2,11,17,35,50]. How obvious would it be that patients should naturally have a role in defining relevant evaluation measures regarding the care they receive?

The way results of the studies are used varies. However, most studies are used for further research and further instrument development. Apart from the relatively small number of studies involved with concrete quality evaluation from patients’ perspectives – which in itself requires improvement – the distribution of studies between the different prevalent purposes implies

something about a common focus of many studies. Purposes like quality improvement and service & outcome evaluation demand concrete measures and concrete study outcomes, forcing researchers to work towards thoroughness and clarity, whereas further research and further instrument development as purposes of study say more about what has to be done yet, than about the merits of the study at issue.

4.1.1. Patient-centred care

Many aspects of care that have emerged in this review and especially in the narratives in the qualitative studies connect with the wider theme of patient-centred care. It shows that patient-centred care has many faces and practices and is of great value for patients. Aspects in which patient-centred care is reflected are for example Patient-provider relationship, Agency & Empowerment, Coping, Wellbeing, Feeling connected, Meaning, and Unmet needs. This wide connection shows that the principle of patient-centred care is actually experienced and valued by the patients in the included studies. As such, AM/IM have a potential to contribute to further develop and enhance the delivery of patient-centred care [17,35,48]. Measuring patient-reported quality of care in AM/IM addresses this principle and provides opportunities to contribute to the evolving research on patient-centred care and its influence on outcomes of care [47,48]. In addition, comprehending the depth and meaning of patient-centred care might be crucial in developing better integration of T&CM with conventional care.

4.1.2. Strengths and limitations

The strength of this study is the rigour of the review, which included many aspects that were collated from the included studies. In addition, it demonstrates that many of the evaluation measures come to together in the overarching theme of patient-centred care. This implies not only a crucial connection between AM/IM and the values of patient-centred care, but also a relevance of this review regarding evaluating patient-centred care within conventional medicine.

A limitation concerns the selection process. Although the greatest care was taken in this, there might exist studies that should have been included, but did not turn up in the search results, due to the phrasing of IM. Only studies that use IM explicitly are included. However, studies that use (a form of) complementary medicine in combination with conventional care without naming this “integrative” in somehow (see search terms) are not included. It was not feasible to include “implicit IM” in the search terms. Also the study did not emphasise on different types of IM. This topic is addressed in for example the review of Lim et al. [8].

The study results might also be limited by the fact that the search took place in February 2017. Possible new studies that have been published between February 2017 and the submission of this study are not included. However, it is commonly accepted that a review is completed within 24 months after the initial search [51].

4.1.3. Implications for further research

This scoping review can contribute to the further development of PREMs and PROMs in AM/IM. The development of a core set of validated PROMs and PREMs for AM/IM in different languages that could be used in many countries is very important for the further global development and scientific underpinning of AM/IM quality of care.

A next step in developing PROMs and PREMs should incorporate a comparison of the existing questionnaires in the quantitative studies and the results from the qualitative studies in this review on item level. Validity and reliability should be considered carefully since the recent systematic review of Bull et al. [52]

Table 4
Patient derived items and/or domains in PREM and PROM development.

Developing prom		Developing PREM	
Verhoef et al., 2005	Physical well-being; Physiological indicators; Emotional well-being; Personal transformation; Feeling Connected; Global sense of well-being; Cure; State of being; Energy; Pain management; Active living	Mulkins et al., 2003	<i>Continue doing:</i> Team approach to their care, Choice of variety of practitioners, Professional and personal skill level practitioners, Basic philosophy, Intake assessment, Caring relationship with practitioners, General atmosphere of clinic; Need improvement: Accessibility, Adding to variety of practitioners, Flexible hours, Information and communication.
Eton et al., 2005	Pain; Fatigue; Physical and functional ability; Personal control; Existential; General quality of life	Keshet et al., 2015	<i>Experience:</i> Practitioner's attitude; Influences of practitioners' attitude
Koster et al., 2016	Recovery/Symptom reduction; Active contribution/Autonomy; General well-being; Meaning; Rest/Relaxation; Functioning; Energy/strength; Care relation; Natural healing; Mindful inner attitude; Being well informed; Social relationships	Koster et al., 2014	Two new CQ-Index scales: <i>1. Interactional style GP:</i> Making comfortable; Showing understanding; Providing insight in background and causes; Providing needed care; Balanced attitude; <i>2. Anthroposophic treatment:</i> AH treatment options; Free choices of treatment options; Focus on physiological self-healing; Patients' own responsibility; Patients' active contribution; Giving meaning; Influence on quality of life
Keshet et al., 2015	<i>Effects:</i> Effectiveness; Coping with distress; Treatment that helped;		
Hunter et al., 2014	Illness and wellness outcomes; Multiple dimensions/ Holistic health outcomes; Subjective patient reported outcomes from patient questionnaires; Patient feedback on physician; Consultation quality; Satisfaction with services		

concluded that these are important limitations of many used PREMs in general.

Remarkably, a large number of non-specific aspects of care were evaluated, both in the qualitative studies and in the quantitative studies. Further research should focus on clarification of these aspects. Clarification could serve three purposes. One, it serves a more concrete and transparent evaluation of AM/IM. Two, the process of clarifying these non-specific aspects adds to the discussion of the influence of non-specific aspects on the delivery of care. And three, insight in these aspects, making them more concrete, will also help to identify factors that contribute to the value and quality of AM/IM in the perspectives of patients.

Further research should also focus on generating more insight in subdomains of the category Patient-provider relationship. In order to develop sound evaluation measures on this particular aspect, results on item level from the selected studies can be added and supported with results from current research on the influence of the patient-provider relationship on treatment processes. Vice versa, results from the selected studies can enhance current insights on the patient-provider relationship with patient-derived knowledge. Fully comprehending the role and influence of the patient-provider relationship on treatment processes, treatment outcomes and the meaning of it for patients might be an important

link in the chain that addresses patient relevant aspects of care in general and the further development of AM/IM specifically.

In addition, the vast prevalence of the aspects Patient-provider relationship and also Agency & Empowerment in the selected studies and the increasing awareness for these aspects in conventional care should be a reason to consider incorporating them as standard aspects in future care evaluation studies.

4.2. Conclusion

Based on this scoping review, the knowledge gap regarding the assessment of patient-reported quality of care within the field of AM/IM can be identified as follows: Patient-reported quality of care was not measured in a standardised and methodologically sound and transparent way. In the quantitative studies, a wide variety of instruments were used, the measured themes differ between studies, and most studies did not give an account for why they chose these particular themes. The large amount of different instruments demonstrates that the field lacks a consensus about a standardised way of measuring patient-reported quality of care. Also, patient involvement in defining which aspects to measure was generally quite low. The qualitative studies did to a large extent investigate and address aspects that were relevant for patients. In the analysis a

meaningful list of themes emerged. However, many qualitative studies remained in a narrative report in which mentioned aspects lacked a formulation in a concrete measurable way.

The results of the studies were used for various purposes. However, the number of studies with (self-reported and implicit) use of results associated with PREMs and PROMs covered only one-third of the included studies. In none of the studies an explicit coherence was made with the theoretical base or definition of IM. In addition, many included studies show evaluation measures that lack specification.

A few promising findings are standing out. Seven domains – Agency & Empowerment; Patient-provider relationship; Perceived effectiveness; Coping & Psychological functioning; Inner awareness; Meaning; and General wellbeing – are most prevalent among the aspects that are derived from patients. Moreover, the theme of patient-centred care is connected with many aspects. Seven studies report concrete, coherent and genuinely patient-derived evaluation measures with emphasis on PROMs and/or PREMs. These are hopefully promising examples that can be used to serve as a base for further development of patient evaluation methods in IM.

4.3. Practice implications

This scoping review could serve as a starting point for the future development of PREMs and PROMs in IM and AM. In doing so a vivid connection – on item level – should be made between existing questionnaires used in the quantitative studies and the results from the qualitative studies. Making a good instrument – one that answers to the key issues validity, reliability and relevance for patients [37,44,46,52,53] – is about bringing together the meaning of qualitative findings and the concreteness of a quantitative instrument. In the end, it is the formulation and nuance on item level that shapes the measure and gives meaning to the instrument.

Authors' contribution

EK was project leader, conducted the search, screened the titles and abstracts, conducted the charting of the data, performed the analysis and drafted the manuscript. EB screened the titles and abstracts in duplicate for eligibility, assessed ten full-text articles for eligibility involving the charting of the data, was involved in the interpretations of the findings and critically revised the manuscript.

DD assessed ten full-text articles for eligibility involving the charting of the data, was involved in the interpretation of the findings, critically revised the manuscript, and supervised the study. All authors read and approved the final version.

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Declaration of Competing Interest

None.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2019.09.010>.

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