

# Patient-centered outcomes on quality of life and anthroposophic healthcare: a qualitative triangulation study

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## Abstract

**Purpose** To provide a qualitative investigation of aspects that matter to patients regarding quality of life (QOL) and other perceived treatment effects of anthroposophic healthcare (AH). It is a first step in the development of patient reported outcome measures (PROMs) for AH. Hence, it will contribute to the evaluation of AH quality from patients' perspectives.

**Method** Within-method triangulation of four qualitative data sources is: (1) Survey of 2063 patients of AH general practitioners; single open item; (2) Survey of 34 patients of AH nurses; single open item; (3) and (4) Sixteen semi-structured interviews with patients. The data sources contained patients' qualitative reports on contribution of treatment to QOL, other perceived treatment effects and/or quality of care aspects. **Content analysis** Construction of items and domains by open, axial and selective coding.

**Results** Twelve domains regarding quality of life are found: Recovery/Symptom reduction, Active contribution/Autonomy, General well-being, Meaning, Rest/Relaxation,

Functioning, Energy/Strength, Care relationship, Natural healing, Mindful inner attitude, Being well informed and Social relations. The interviews demonstrate relations between domains.

**Conclusions** The findings give a comprehensive insight into aspects of care that are relevant to patients, providing a first step to develop PROMs for AH. Findings show a broadening of domains compared to existing measurement instruments and show close similarities with the recently developed concept of "positive health." Extending QOL instruments with a broader set of domains would give concrete tools to improve evaluation of quality of care and make this evaluation more in line with aspects that matter to AH patients.

**Keywords** Quality of life · Quality of care · Patient reported outcomes measures · Patient-centered care · Anthroposophic healthcare · Qualitative triangulation

## Introduction

In the last two decades, patients' perspectives on quality of care have become increasingly important in the evaluation of healthcare performance [1, 2]. Patients' perspectives are addressed by measuring patient *experiences*—with consumer assessment questionnaires such as CQ-Index, CAHPS and QUOTE [3]—as well as by measuring patient reported *outcomes* (PROs) [4–7].

Evaluating quality of care from patients' points of view is also relevant for integrative medicine (IM) and anthroposophic healthcare. IM is the practice of medicine, founded on four pillars: (1) it is informed by evidence, (2) it reaffirms the patient–practitioner relationship, (3) it focuses on the whole person and (4) it makes use of all

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appropriate therapeutic approaches, professionals and disciplines to achieve optimal health and healing [8, 9]. IM is increasingly practiced worldwide [10–12].

Anthroposophic healthcare (AH) is a form of IM, originating in Europe and currently practiced in 80 countries worldwide [13]. It underlines the four pillars and integrates them in a whole system approach based on anthroposophic philosophy. AH uses all knowledge of conventional medicine and adds to it a holistic view on life and a focus on salutogenic health promotion [13–18]. AH encompasses multiple medical sectors, among which are general practice, specialists' care, nursing, child welfare centers (CWC) psychiatry and special needs care, and a variety of paramedic disciplines, for example, physiotherapy, art therapy, eurythmy therapy and psychotherapy.

The quality and quantity of the scientific underpinnings of AH are growing [15, 19–23]. Recently, in the Netherlands, patient experiences with AH were measured by means of a CQ-Index AH [24]. According to this study, the service quality of AH and interpersonal relations between physicians and patients are good and general rating is slightly higher than of conventional healthcare [25]. In addition, in order to evaluate the effectiveness of AH with similar methods as those used in other healthcare sectors, it is important to develop PRO measures (PROMs) for AH [26].

To develop PROMs for a group of patients, it is important to start with a qualitative phase in order to investigate what aspects of care are relevant to these patients [4–6, 27–29]. An important concept that is regarded to be particularly relevant to patients is quality of life (QOL) [7, 30, 31]. The QOL concept intends to cover all aspects of human experiences of what makes a life a good life [30, 32, 33]. The concept QOL has been adapted in order to measure quality of life related to health and illness: health-related QOL (HRQOL) [30]. Existing HRQOL measures are often used as PROMs, for example SF-36, EuroQol-5D and WHOQOL-BREF [6, 7, 28, 31, 33]. Hence, QOL is used as an outcome factor in measuring quality of care. Often used domains of HRQOL are given in Table 1 [34–36]. Considering their general character,

these HRQOL measures could be used as PROMs in AH as well. However, being a form of integrative medicine AH encompasses more aspects of life than conventional medicine. It is not known whether existing QOL measures will be sufficient to serve as PROMs for evaluating AH and whether these instruments measure what is relevant for AH patients.

An aspect that might be important for the development of good PROMs for AH is the fact that within AH the centrality of patients within their own treatment is very strong. Patients are not only cared for according to their individual needs and preferences, taking into account all aspects of human life, but also actively stimulated to care for themselves, to contribute to their own health and are provided with practical guidance to do so [19, 37]. Because AH is being practiced for over 90 years [13], one can say that AH practices patient-centered care (PCC) *avant la lettre*. Therefore, this characteristic of AH might not only be important in developing good PROMs for AH, but also be relevant for the further development of PROMs in general. Overall, it is important to start with a general and open investigation.

### This study

Addressing the importance of a qualitative phase regarding the development of PROMs, this study aims to provide a comprehensive insight into outcome aspects of care that are important to AH patients. The study investigates how treatment influences and affects QOL from the perspective of patients and does so without a theoretical preconstruction of QOL. The study focuses on actual *experiences* with treatment and its effect on QOL rather than collecting patients' *ideas and opinions* on how treatment *should* contribute to QOL. In addition, the study investigates other perceived treatment effects and aspects of care that matter to patients.

The study will be a first step in developing new PROMs or choosing appropriate existing PROMs to evaluate outcomes of AH. Hence, it will contribute to the evaluation and accountability of the quality of AH from patients'

**Table 1** HRQOL domains often used

EuroQol-5D	SF-36	WHOQOL-BREF
Mobility	Physical functioning	Physical
Self-management	Limitations caused by physical problems	Psychological
Pain and other complaints	Pain	Environmental
Daily activities	Perceived general health	Social
Fear and depression	Limitations caused by emotional problems	
	Vitality	
	Mental health	
	Social functioning	

perspective. In addition, the results might provide valuable information for the further development of PROMs in general.

The following research questions were addressed:

1. How do patients experience AH treatment and its effects on their health and QOL?
2. What are characteristics of AH contributing to quality of care from the perspectives of patients treated by AH professionals?

## Method

The research design encompassed secondary analyses on existing qualitative data from earlier studies, collected using within-method triangulation [38, 39] of four different data sources and two different data collection procedures: surveys and in-depth interviews. Researchers used an inductive method in the sense that the analyses were performed sequentially; however, the data collection had taken place in tandem. The order of analyses was decided based on the size and collection method of the data sources: first the largest data source, followed by the second largest one, both short single open items. After that, the interviews were analyzed in order to deepen the insight.

### Data collection

Details of the data collection are given in Table 2.

#### Data source 1

Data source one (DS1) contained the results of a qualitative survey among 2063 patients of anthroposophic general practitioners (GPs). The respondents of the CQ-Index AH were asked: *Did the treatment contribute positively to your quality of life?* Followed by: *If so, could you point out how?* Respondents gave a short open answer. The data collection was part of the validation study of the CQ-Index AH [24].

#### Data source 2

Data source two (DS2) contained the results of a qualitative survey among 34 patients of anthroposophic nurses, who treated their patients with external applications therapy (massages, packs and baths with oils, essences and/or ointments).

Therapy consisted of 12 one-hour sessions. Patients were asked about perceived treatment effects by completing the following sentence: “Often when I have had

external application treatment:...” Respondents gave a short open answer. The item was part of an outcome questionnaire within a pilot project developing a routine outcome monitoring procedure in external applications therapy [40]. It was asked at three points in time: after, respectively, four ( $t = 1$ ), eight ( $t = 2$ ) and twelve ( $t = 3$ ) sessions.

#### Data source 3

Data source three (DS3) contained the results of six semi-structured interviews with patients evaluating their experiences with an anthroposophic care program for depression [41]. The topic list included: evaluation of treatment, provider–patient relationship, perceived treatment effects and view on illness and health. The interviews were part of a pilot study developing the care program. The patients were recruited from participating GP practices. Inclusion was based on severity of depression, using PHQ-9 questionnaire [42].

#### Data source 4

Data source four (DS4) contained the results of ten semi-structured interviews with patients of AH treatment of various disciplines. The main theme of the interviews was patients’ experiences with health promotion. The topic list included: one’s own role regarding treatment and health promotion; coping with pain and anguish; responsibility of provider and patient; role of AH regarding health promotion; individual needs regarding health promotion and support. Respondents were selected from the Dutch anthroposophic patients’ organization. Illnesses of respondents varied between minor illnesses (e.g., colds, low HB), chronic diseases, combinations of mental and physical illnesses, allergies, aging problems and life-threatening diseases (e.g., heart failure and cancer).

### Response analyses

The net response of DS1 was  $N = 866$ . Because non-singular answers were split, there were more answers than net respondents. The number of total valid answers was  $N = 1050$ . The net response of DS2 was  $N = 30$ . Because this research does not include changing effects over time answers of  $t = 1$ ,  $t = 2$  and  $t = 3$  were added up, and again, non-singular answers were split. The number of total valid answers was  $N = 141$ .

Details of the response analyses are given in Table 3 (DS1) and Table 4 (DS2). The response analyses for DS3 and DS4 are given in Table 5.

**Table 2** Details on data collection

Data source	Earlier study	Collection method	Data collection Period	Population	Inclusion criteria	Exclusion criteria	Question/topic list	Data collection by researcher
DS1	Validation study CQ-Index anthroposophic healthcare	Survey Single open item with a short open answer	Sept 2010–April 2011	Patients of anthroposophic GPs	All patients participating in the validation study >18 years of age	CQ-Index participation in the last 12 months	<i>Did the treatment contribute positively to your quality of life? Followed by: If so, could you point out how?</i>	EK and EB
DS2	Routine outcome monitoring of external applications therapy in primary care: a pilot research	Survey Single open item with a short open answer	March–June 2011	Patients of anthroposophic nurses	All new patients during a four-month period	<18 years of age	Completing: “Often when I have had external application treatment:...”	EB
DS3	Development of a anthroposophic care program for depression	In-depth interview Semi-structured 1–1.5 h Location: healthcare center	October–November 2012	Patients of anthroposophic GP's	All patients participating in the care program 18–65 years of age Mild and moderate depression, measured by PHQ-9 questionnaire, score >5 and <19	Weak or decreasing cognition	Evaluation of treatment, provider–patient relationship, perceived treatment effects, and view on illness and health	NR
DS4	Interviews on health promotion	In-depth interview Semi-structured 1–1.5 h Location: research institute	June 2010	Patients from Dutch anthroposophic patient organization	<i>Individual level:</i> Actively involved with own treatment <i>Group level:</i> 1. Both men and women 2. A variety of age 3. Different education levels 4. Different illnesses Patients of different care providers	<18 years of age	One's own role regarding treatment and health promotion; coping with pain and anguish; responsibility of provider and patient; role of AH regarding health promotion; individual needs regarding health promotion and support.	EK

## Data analyses

The data analysis process consisted of content analyses in four phases, using coding elements from grounded theory: open, axial and selective coding [43–45]. Details on applying the coding process are explained in Table 6. The amount of answers suggests that sufficient data saturation will be likely, which will be discussed in the discussion section.

### Phase 1

DS1 was open coded by two researchers individually (EK, NR) and subsequently checked on four methodological criteria—overlap with other items, ambiguity, singularity and concreteness [46]. Answers with overlap, those that were ambiguous or lacked concreteness were deleted. To prevent losing important information, answers containing more than one aspect were split. These were coded and again checked for each item individually. Researchers each made an independent coding list. After individual coding, the researchers discussed and integrated both coding lists. Thereafter, axial coding was applied.

### Phase 2

The individual items were clustered into domains, and these were given a preliminary label. Five co-workers (EK,

NR, EB, ETK, AB) discussed the clusters. Within this group doubts and different interpretations were discussed for each item, resulting in a consensus-based list of domains.

### Phase 3

The coding list was applied to the open answers of DS2. The answers were checked for the same methodological criteria as DS1 and deleted or split the same way. Similarities, differences and additions were integrated into the coding list, and necessary adjustments were made to the domains.

### Phase 4

DS3 and DS4 were analyzed using selective coding [43, 47]. Consequently, labeled domains were compared to the found themes in the interviews. Researchers specifically looked at commonalities between the themes found in the different data sources and the interpretations of those themes by the respondents in the interviews. The domains were extended and refined accordingly. Then, researchers looked for specific relations between different domains. During the coding process, text passages emerged coded with more than one domain. The relationship between domains in the particular passage was analyzed from the content of this passage. After these final analyses, the domains were given definitive labels.

**Table 3** Response analysis data source 1

	<i>N</i>	%
Sample size	2063	100
Gross response	1034	50
Non-valid	74	
Methodological criteria	94	
Net response	<b>866</b>	42
Valid first answer	866	
Valid second answer	160	
Valid third answer	24	
Total valid answers	<b>1050</b>	

**Table 4** Response analysis data source 2

	Total	<i>T</i> = 1 ( <i>N</i> )	<i>T</i> = 2 ( <i>N</i> )	<i>T</i> = 3 ( <i>N</i> )
Gross response	<b>34</b>	–	–	–
Non-valid	<b>4</b>	–	–	–
Net response	<b>30 (88 %)</b>	–	–	–
Valid first answer	<b>82</b>	27	30	25
Valid second answer	<b>45</b>	17	18	10
Valid third answer	<b>14</b>	7	5	2
Total valid answers	<b>141</b>	51	53	37

**Table 5** Response analyses data source 3 and 4

	Data source 3	Data source 4
Men	3	4
Woman	3	6
Mean age	51.8	49.6
SD	10.23	17.54

**Table 6** Details on content analysis process

Data source	Phase 1 DS1	Phase 2 DS1	Phase 3 DS2	Phase 4 DS3 and DS4
Analysis on item level	<p><i>Open coding:</i></p> <p>Labeling all individual answers by two researchers independently.</p> <p>Synchronizing similar labels and two coding lists, resulting in one new list.</p> <p><i>Axial coding:</i></p> <p>Applying new coding list on original items.</p> <p>Comparing and making adjustments.</p>		<p><i>Axial coding:</i></p> <p>Applying and comparing coding list to items of DS2</p> <p><i>Open coding:</i></p> <p>Adding new items in domain structure.</p>	
Quality check of items on:	<p>Concreteness</p> <p>Ambiguity</p> <p>Singularity</p> <p>Overlap</p>		<p>Concreteness</p> <p>Ambiguity</p> <p>Singularity</p> <p>Overlap</p>	
Analysis on domain level		<p>Clustering items into domains</p> <p>Consensus of domain structure and coding list</p> <p>Discussion of doubts</p>	<p><i>Open coding:</i></p> <p>Adding new domains to domain structure.</p>	<p><i>Axial and selective coding:</i></p> <p>Checking and coding of domains in content of interviews.</p> <p><i>Open coding:</i></p> <p>Adding new information into domains structure</p> <p><i>Selective coding:</i></p> <p>Text passages coded with more than one domain.</p> <p>Analysis of relationship from content of passage</p>
Analyses relationships between domains				

## Results

### Items and domains

Analysis of DS1 led to formulation of eleven domains regarding QOL: 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. A list of all domains and items is given in Table 7. All answers of DS2 correspond with seven domains of DS1: Active contribution/Autonomy, General well-being, Rest/Relaxation, Functioning, Energy/Strength, Natural healing, Mindful inner attitude (Table 7).

All domains from DS1 and DS2 are covered by the content of DS3, and one domain is added: *Social relations*. In contrast to DS1 and DS2, answers of DS3 had more explicit attention for characteristics of one's treatment, regardless its effect. Most frequently mentioned in DS3 is the involvement of patients' GP and therapists with the

patient. People valued their treatment especially for the way that it suits, for example, their situation, personality, preferences, worldview and/or their life. The treatment is personally tailored regarding all aspects of life. This way, patients are seen and heard as whole human beings. The theme of personally tailored treatment is not added to the domains, because aspects of it are grouped in other domains, according to their content. Answers of DS4 were mainly focused on *self-regulation* (domain: *Natural healing*), *tools for coping* (Active contribution/Autonomy), *Functioning*, *Mindful inner attitude* and *Meaning*. A new item that emerged was *contact with nature* (Active contribution/Autonomy).

### Relationships between domains

The stories from the interviews showed that domains and subdomains interact with each other. From this interaction relationships could be interpreted. First, the relationship is described, and then, this is illustrated with quotes from the interviews.

**Table 7** Total domains, subdomains and items (data source 1–4)

Domains	Subdomains	Items
Recovery/Symptom reduction		Specific illness recovery Specific symptom reduction Speed of Recovery/Symptom reduction
Functioning*		Physical functioning Mental coping Less absence Doing enjoyable things Assertiveness Balance work/relaxation Less surviving
Natural healing*		No/less adverse events No conventional medication Physiological self-regulation supported/used Treatment offers general support Specific physical reactions on treatment**
Rest/Relaxation*		Better sleep during the night Satisfying tiredness** “Rosy-ness”**
Care relation		Trust and confidence in doctor Communication Human approach Being at ease
	Attention	Being heard/seen Being understood Taken seriously Feeling supported
General well-being*		Feeling better (“ <i>beter in mijn vel</i> ”) Feeling of optimism/happiness/lust for life Balance/wholeness/harmony
Social relations***		Better partner relationship Better social life Close to family
Energy/Strength*		Physical condition Balanced energy level Improved vitality Feeling physically stronger Stronger muscles Resilience Resistance
Being well informed		Good information Monitoring Appeasement

**Table 7** continued

Domains	Subdomains	Items
		Relief
Mindful inner attitude*	More attention/awareness	Self awareness
		Emotional reactions on treatment** Body awareness Taking time for things**
	Positive attention/awareness	Acceptance
		Emphasize on positive things Faith and hope Confidence in own body
Meaning		Insight regarding health and disease Giving meaning within the big picture Personal development Holistic vision Treatment fits own vision on life
Active contribution/Autonomy*		Keystones/tools for coping Own responsibility Grip/control/own control Self-confidence
	Healthy lifestyle	Food No smoking Contact with nature***

\* Domains corresponding with data source 2

\*\* New added items from data source 2

\*\*\* New added domain and item from data sources 3 and 4

*Active contribution/Autonomy, Rest/Relaxation, Functioning, General well-being and self-regulation*

Self-regulation was related to several other (sub)domains. Domains like *Active contribution/Autonomy and Rest/relaxation* turned out to function as an investment in respondents’ self-regulation. The respondents actively endeavored a lifestyle with sufficient room for their self-regulation to function properly. Aspects of this lifestyle were good food, physical exercise, rest, daily rhythm, doing enjoyable things and contact with nature. Respondents described the positive effects as “*recharging*.” Other domains such as *Functioning and General well-being* turned out to benefit from a well-maintained self-

regulation. Recharging enabled respondents to function better or, like a respondent said: “*to look at the world as fresh and friendly again*” (DS4). Because the investment and benefit partly overlapped, a loop of positive feedback could develop in maintaining a well-functioning self-regulating ability.

#### *Positive awareness and self-regulation*

Being aware of one’s own body increased the contact with one’s self-regulating ability and improved one’s General well-being. Respondent: “Rhythmic massages made me feel stronger and reduced my stress symptoms” (DS4). Faith regarding one’s self-regulating ability turned out to be a crucial factor here. Respondent: “Maintaining faith [EK: in the treatment process] is an active process that constantly needs attention” and “I’ve always said: This is not going to make me die” (DS4).

#### *Active contribution/Autonomy and Being well informed*

Several domains were used as resources regarding active contribution and autonomy. The respondents deemed it essential to be well informed to be able to make their own choices fitting their own personal preferences and situation. Respondent: “To have different possibilities to choose, no matter how small, helped me to feel less overwhelmed by everything, (...) by making the little steps I had chosen myself I could get used to changing situations easier and that made me cope with and accept the current situation better” (DS4).

#### *Being well informed, Functioning and Meaning*

Respondents valued a thorough insight of “what is going on.” This insight enabled them to give meaning to their own situation. This meaning influenced patients’ inner attitude toward their impairment positively and that improved integration of it within daily functioning. Respondents asked themselves how their daily functioning contributes to their impairment and what they can do to reduce the symptoms. One respondent argued that healing is only possible after you have accepted your problem and it is fallen into place. Respondent: “You have to embrace your illness” (DS4).

#### *Meaning and Care relation*

An open, holistic view from the care provider contributed to an equal care relationship in which the patient experienced that he/she is fully seen and heard as a whole human being. One respondent feels heard “...because he [EK: care provider] asks questions and truly looks at what is going on

with me” (DS3). Another respondent: “You just want to be seen as a person” (DS3).

#### *Active contribution, self-regulation and Care relation*

An active contribution to one’s own health was anchored within an involved and equal care relationship. Respondent: “Doctors should ask: What would help you, in your situation?” (DS4). In the common search for an individually tailored treatment there was much attention and support for self-regulation. The use of self-regulation offered the particular individual practical keystones for coping and, in doing so, increased possibilities to actively contribute to one’s own health. For instance, adapting previously mentioned lifestyle aspects to their individual treatment. This opened up a professional tailored form of self-care, embedded in their individual treatment. Subsequently, it offered additional possibilities to address previously unaddressed problems. Respondent: “Keeping myself warm is a very simple and effective way to reduce the pain of my arthrosis” (DS4).

## **Discussion**

This study investigated patients’ experiences with AH treatment and its perceived effects on their health and QOL. It provides a comprehensive insight into aspects of QOL and AH that are relevant to AH patients. Hence, it reveals characteristics of AH that contribute to the quality of AH from patients’ perspectives.

Analyses of four data sources led to formulation of 12 domains, containing aspects of AH treatment that contribute to patients’ QOL. They are: *Recovery/Symptom reduction; Active contribution/Autonomy; General well-being; Meaning; Rest/relaxation; Functioning; Mindful inner attitude; Energy/strength; Care relation; Natural healing; Being well informed; and Social relations*. The in-depth interviews provide insight into relationships between domains.

The results show perceived effects of AH according to patients, and a wide variety of treatment aspects contributing to patients’ QOL. The aspects are intelligible, concrete and fit into relevant domains. Due to the amount of and the similarity in answers, the researchers expect that they have covered all possible domains. The richness and methodological quality of the answers show that respondents are very well capable of reflecting on their QOL without responding to a theoretical preconstruction of the concept. The emphasis on direct experiences with received care contributes to the validity of the answers for practical use in comparison to answers based on ideas and opinions. The results show from different angles or perspectives, in



different data sources, similar answers emerged. In the context of within-method triangulation, these different perspectives contribute to the validity of the findings.

The quality of the results enables this study to be used as starting point for the development of PROMs for AH. On a broader scale, the results will contribute to the scientific underpinnings of AH and a transparent, comprehending communication inside and outside its field.

A limitation concerns the fact that the data collection methods are designed to serve the earlier studies in the first place. A second limitation concerns the fact that the answers are provided by patients from AH providers. Because this might be a specific patient, group it challenges the generalizability of the findings. However, DS1 and DS3 included patients of GPs with a mixed practice population: Some patients may have chosen their GP because of anthroposophic background; others simply because it was the closest available option, or other non-AH-related reasons. Further research needs to be done to investigate differences in needs between different patient groups.

The domains that emerged from the study partly overlap with the domains of existing instruments such as SF-36 [34], EuroQol [36] and WHOQOL-BREF [35].

*Functioning* overlaps with physical functioning (SF36), mobility and daily activities (EuroQol) and the physical domain (WHOQOL), *General well-being* overlaps with perceived general health (SF-36) and overall (WHOQOL), *Social relations* overlaps with social functioning (SF-36) and social domain (WHOQOL), *Recovery/Symptom reduction* overlaps with pain (SF-36), and pain and other complaints (EuroQol), and *Energy/Strength* overlaps with Vitality (SF-36). New items within these overlapping domains are: less surviving (*Functioning*), feelings of balance/wholeness/harmony (*General well-being*), speed of recovery (*Recovery/Symptom reduction*) and resilience (*Energy/Strength*).

Seven new domains emerged: *Active contribution/Autonomy*, *Mindful inner attitude*, *Being well informed*, *Care relation*, *Natural healing*, *Rest/Relaxation* and *Meaning*.

The domain *Active contribution/Autonomy* seems to overlap with the domain self-management from the EuroQol. However, on item level they show a different content. In addition, the aspect of *Meaning* is also present in the WHOQOL. However, it is present as a single item, being part of the psychological domain, while in the current study it emerges as a domain of itself.

Some of these domains, such as *Being well informed* and *Care relation*, are not new in evaluating healthcare performance. However, these are usually addressed as experience measures, for example in CQ-Indexes [3, 4], instead of outcome measures, like PROMs. Altogether, the study demonstrates a broader view on health, QOL and outcomes of care from patients' perspectives than current HRQOL instruments.

A broader view on health and QOL is also demonstrated in the work of Huber et al. [48], who recently proposed to change the WHO definition of health. They redefined health as a dynamic construct based on “the ability to adapt and self-manage” [48]. Extended research to the ability to operationalize the new definition provided six main dimensions: *body functions*, *mental functions and perceiving*, *spirituality*, *quality of life*, *social and societal participation* and *daily functioning* [49]. Based on these dimensions Huber et al. [49] developed the concept of “positive health.”

This new view on health shows important similarities with the results in our research. Firstly, there is a close similarity in content between the domains of *General well-being* in this study and *quality of life* in Huber et al., particularly the items of feeling better, happiness, lust for life and balance. Secondly, both studies demonstrate the importance of autonomy, manageability, self-esteem, self-management and own control regarding health and QOL. Thirdly, both studies contain a full and separate domain for the aspect of meaning. This shows the importance of being able to give meaning to problems and situations in order to cope with them and live a “full” life.

In addition, in both studies the aspect of self-regulation plays an important role. In Huber et al. [48, 49], it is very much connected with health in general, because it is present in the definition as the “*ability to adapt and to self-manage*,” both physically and mentally. In our study, self-regulation is present in, for example, the domain *Natural healing*, as physiological self-regulation and in the domain *Active contribution/Autonomy*, as tools for coping. In both studies it is the individual that contributes to its own recovery.

The new concept of health has been widely recognized, in many different healthcare settings [50–54].

Also in the field of psychology, efforts have been made to broaden concepts of health and QOL. Seligman speaks of positive psychology, encompassing three domains: *pleasure*, *engagement and meaning* [55, 56]. Ryff named six domains of well-being: *autonomy*, *environmental mastery*, *personal growth*, *positive relations with other*, *purpose in life and self-acceptance* [57]. Moreover, the similarities between our study, the work of Huber et al. and similar work in the field of psychology imply that the results of the current study might be relevant for healthcare settings outside the field of AH as well.

In addition, Ryffs domains are used to develop a measurement instrument for evaluating well-being therapy [58]. This instrument might not only be useful in finding or constructing appropriate PROMs for AH, but also be relevant for complementing existing PROMs in other healthcare settings.

Future research needs to investigate whether PROMs for AH could be constructed from appropriate existing instruments or that a new instrument needs to be developed.

If so, research should focus on prioritizing domains by patients and subsequently converting them into a validated measurement instrument. Future research also needs to investigate whether patients of conventional medicine and other integrative medicine providers generate similar results. In general, to make evaluation of healthcare more in line with what is relevant for patients, QOL measures should be extended with a broader set of domains. And in doing so, it might be useful also to consider research in other fields, such as psychology, and integrate it into the field of medicine.

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**Author's contribution** EK was project leader, did the interviews of DS4, performed analyses and drafted the manuscript. EB generated DS2, participated in the design of the study, was involved in the interpretations of the findings and critically revised the manuscript. DD was involved in the interpretation of the findings, involved in writing the manuscript and supervised the study. All authors read and approved the final version.

#### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was exempted from a medical ethics committee approval because the study contained the monitoring and evaluation of current practice, and participants were not subject to any experimental conduct or imposed behavior [59]. However, all four data collection procedures are conducted in accordance with necessary ethical guidelines.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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