

Development of a self-report questionnaire to assess the impact of rheumatic diseases on health and lifestyle

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Samenvatting

Het begrip gezondheid omvat lichamelijke, psychologische en sociale aspecten. In dit artikel beschrijven we de ontwikkeling van de IRGL (Invloed van Reuma op Gezondheid en Leefwijze: een Nederlands zelfbeoordelingsinstrument om gezondheid te meten bij patiënten met reuma). Lichamelijk welbevinden wordt gemeten middels de schalen: mobiliteit, zelfredzaamheid en pijn. Psychologisch welbevinden middels de schalen: angst, sombere- en opgewekte stemming. Sociaal welbevinden is onderverdeeld in sociaal netwerk (aantal vrienden en aantal buurtgenoten met wie men contact heeft) en in sociale steun (potentiële- en feitelijke veroudering en wederzijds bezoek). Daarnaast is een interferentie of 'impact' schaal opgenomen, waarmee de invloed van reuma op diverse levenssterreinen nagegaan wordt. In het onderzoek naar de psychometrische kwaliteiten van de IRGL werden in totaal 433 patiënten met reumatoïde artritis betrokken. Op grond van de resultaten kan geconcludeerd worden dat de IRGL als instrument om de gezondheid van RA-patiënten te meten in voldoende mate betrouwbaar en valide is.

Trefwoorden

Reumatoïde artritis, gezondheid, zelfbeoordelingslijst, meetinstrument, kwaliteit van leven.

Summary

Health may be broadly defined as a state of physical, mental and social well-being. This article describes the development of the IRGL; a Dutch multidimensional instrument for measuring the health status of patients with rheumatic diseases. Physical well-being is measured by the mobility, self care and pain scales; psychological well-being by the anxiety, depressive and cheerful mood scales. Social well-being is subdivided in social network indices (number of friends and number of contacts in neighbourhood) and social support scales (potential support, actual support and mutual visits). An impact scale is also included to assess the influence of rheumatic diseases on various domains of daily life. Psychometric qualities of the IRGL were determined based on data from 433 patients with rheumatoid arthritis. Findings of this study demonstrate that the IRGL is a reliable and valid instrument for measuring health status of RA-patients.

Key words

Rheumatoid arthritis, health, self-report questionnaire, measuring-instrument, quality of life.

Introduction

In 1958 the World Health Association defined health as physical, mental and social well-being (WHO, 1958). This 30-year-old WHO-definition gave an impuls to a development in health care and health research, which attached more importance to psychological and social factors of chronic diseases such as rheumatoid arthritis (RA). As crucial factors in the health status of patients with RA the following aspects are mentioned: activity of the disease, functional capacity, pain, mental and social problems, such as depressiveness, anxiety and social isolation (Anderson et al., 1985; Frank et al., 1988; Genest, 1983; Huiskes & Bijlsma, 1989). For the outcome-assessment it means that not only physical aspects but also psychological and social aspects of health ought to be evaluated (Bijlsma et al., 1990b). Therefore several self-report questionnaires were developed in the last decade, the most important being: the Arthritis Impact Measurement Scales, AIMS (Meenan, 1986), the Health Assessment Questionnaire, HAQ (Fries et al., 1980) and the Sickness Impact Profile, SIP (Berger et al., 1981). In the meantime translations have been made of the SIP (De Witte et al., 1987), the AIMS (Taal et al., 1989a-b) and of the physical/functional part of the HAQ (Siegert et al., 1984; Bijlsma et al., 1990b). The purpose of the study presented here is the development of a reliable and valid self-report questionnaire specifically designed for the Dutch situation to assess physical, mental and social aspects of health in patients with RA, called the IRGL (Invloed van Reuma op Gezondheid en Leefwijze = Impact of Arthritis on Health and Lifestyle).

Method

Because of the conformity of the AIMS-item subdivision and the WHO-definition of health as physical, mental and social well-being the AIMS was chosen as a starting-point for the development of the IRGL. Not only does the AIMS-design resemble the WHO-definition of health, but it also measures an important aspect, namely pain. Furthermore, much has been published on the psychometric qualities of the AIMS. The selection-procedure of the IRGL-items has been elaborately presented elsewhere (Huiskes et al., 1988; 1990a; 1990b). Here a short description is given.

Although the development of the IRGL is partly based on the American AIMS, it is not simply a Dutch translation of the AIMS. Our purpose was to develop an instrument specifically for the Dutch situation. Furthermore many changes in the AIMS-design had to be made to overcome certain psychometric problems. For example the AIMS is not consistent in the used response categories and some items are ambiguously formulated. In the IRGL we chose

for a 4-point scale (almost never-sometimes-often-almost always) as response category for most of the items indicating the frequency that one is actually able to perform certain activities. Furthermore the items used in the psychological and social scales were not derived from the AIMS, but from Dutch instruments. This sample of IRGL-items was administered to 171 out-patients with classical or definite RA. All patients were older than 18 years. Prior to administering the questionnaire clinical and laboratory tests were done by the rheumatologist to measure the activity of the disease. Patients were also classified according to the ARA functional classes (Steinbrocker et al., 1949).

Statistical analysis on the data was performed, which led to a more compact definitive version of the IRGL.

The physical, psychological, social and impact scales were compiled as follows.

Physical well-being

The items in this scale were selected according to their informative value. An item was considered informative if the scores had sufficient variability. All non-informative items were removed. A factor-analysis was performed on the 21 remaining items. This yielded the following scales: mobility (7 items), self care (8 items) and pain (6 items).

Psychological well-being

In order to measure anxiety and depressiveness we used instruments that were found reliable and valid for the Dutch population. For anxiety we used an abridged version (10 items) of the 'Zelfbeoordelingsvragenlijst', ZBV (Van der Ploeg et al., 1980). For the assessment of depressiveness we used the 'Stemmingenlijst', which consists of 6 items for depressive mood and 6 items for cheerful mood (Zwart & Spooren, 1982).

Social well-being

The AIMS uses the scale 'social activities' to measure social well-being. This scale refers only to the frequency of ones contacts. Our definition of social well-being is somewhat more differentiated. We concur with the theory of social support (a.o. Cohen & Wills, 1985; Garssen et al., 1985). Not only quantitative aspects of social support, such as the extent of social network, are of importance, but also more qualitative aspects, such as the degree of involvement and support one experiences. In the IRGL two items assess quantitative aspects of social support, namely: the number of friends and the number of neighbours one associates with. There are eleven qualitative oriented items, most of which were taken from the questionnaire 'Sociale Contacten' (Garssen, 1986). Analysis of these eleven items yielded three scales: potential exchange of emotional support (seeing the possibility to exchange joys and sorrows), actual exchange of emotional

support (actual confidential interaction) and mutual visits (Van Dam-Baggen, 1989).

RA Impact

In the AIMS the impact of RA on daily life is measured by a visual analogue scale. In the IRGL this item is specified for several domains of daily life, which can be affected by rheumatic diseases. For instance work, hobbies, relationships and sexuality.

This definitive version of the IRGL consists of 68 items in total and takes 20 minutes to complete. A review of the items can be found in the appendix. This version was sent to 500 RA-outpatients in the vicinity of Utrecht. These patients were randomly selected from the Department of Rheumatology of three hospitals; Academic Hospital and Diakonessenhuis in Utrecht and the St. Antonius Hospital in Nieuwegein. All patients had classical or definitive RA. The minimum age was set at 18 years.

Results

Of the 500 patients the questionnaire was sent to, 85.2% (N=426) responded. Of these sixty-four questionnaires appeared not to be useful. Our data are based on the remaining 362 questionnaires. This sample exists of 66% female and 34% male with an average age of 60 years. Most patients were married (70%) and did have an education level (lower and intermediate vocational education - 83%) comparable with their age-group in the Dutch population. Similar demographic data were found in a previous Dutch research (Cornelissen, 1984). The average age at onset of the disease was 45 years and the average duration of the disease 15 years. Women had their first symptoms at a younger age than men (43 years vs 48 years). These demographic data concur with what is known of RA-patient populations (Gran, 1987).

Reliability and validity

Reliability of the IRGL-scales was assessed using Cronbach's alpha, a measure for internal consistency. This alpha coefficient indicates whether the items of a scale measure the same aspect. The closer the value is to 1, the higher the homogeneity of the scale. The standardized alphas for scales with more than three items are: mobility .92, self care .90, pain .86, depressive mood .92, cheerful mood .91, anxiety .87, potential support .88, actual support .66, impact .87. These alpha values indicate a high internal consistency of the IRGL-scales. The scale 'actual support' has a relatively lower alpha value, but still is quite acceptable. To determine the construct-validity of the IRGL we performed a factor analysis on the scales. The impact-scale was excluded from this factor analysis as we assumed that physical, psychological and social aspects all have an influence on the impact. As is shown in table 1 three factors were found, namely: psychological,

Scale	Factor 1 (Psychological)	Factor 2 (Physical)	Factor 3 (Social)
Physical			
1. Mobility	.07	.82	.14
2. Self care	.08	.87	.05
3. Pain	-.29	-.71	
Psychological			
4. Depressive mood	-.84	-.22	-.04
5. Cheerful mood	.82	.03	
6. Anxiety	-.85	-.24	
Social			
	.01	.21	.70
8. Nr. of good friends	.09	.01	.75
9. Potential support	.58	.03	.32
10. Factual support	.24	-.21	.60
			.61

Table 1. Factors analysis of 11 IRGL-scales (N=362)

physical and social well-being. The criterium-validity of the physical scales was determined by data from the rheumatological examination. This examination used the Ritchie's Articular Index (Ritchie et al., 1968) to assess the number of tender and swollen joints, walking time (30 metres) and grip strength. The functionality of the patient was rated according to the ARA-functional classification. Laboratory tests were done to determine the sedimentation rate (ESR), C-reactive protein (CRP), haemoglobin (Hb) and thrombocytes (Thr).

Significant correlations between clinical and laboratory findings and the physical status as measured with the IRGL was found. Table 2 summarises these findings.

The above mentioned results indicate that the IRGL is a reliable and valid instrument for the assessment of health in patients with RA.

Discussion

The IRGL is a self-report questionnaire for the assessment of physical, psychological and social well-being in patients with a chronic rheumatic disease. Psychometric research of the IRGL was so far based on patients with rheumatoid arthritis. Patients with other rheumatic diseases ought to be included in further research with the IRGL. The reliability of the IRGL-scales, determined by the alpha coefficient for internal consistency was very high. In a second-order factor analysis three factors were found, which were in conformity with the aspects the IRGL aims at assessing; that is to say physical, psychological and social well-being. These three aspects of health seem to be better represented by the IRGL in comparison with the AIMS (Meenan, 1986) or the DUTCH-AIMS (Taal et al., 1989). These results support the construct validity of the IRGL as an instrument for the assessment of physical, psychological and social aspects of health in patients with RA.

The criterium-validity of the IRGL-scales for physical well-being was supported by the significant correlations

with clinical and laboratory measures. An explanation for the higher overall coherence of the IRGL-scales for physical well-being and clinical findings probably lies in the greater comparability of their nature. The laboratory measures are process rather than outcome measures and do not directly measure health status, but mainly assess disease activity. As such these laboratory measures correlate poorly with the self-reported functional capacity and pain. Furthermore if one takes a closer look at the height of the various significant correlations it was found that self-report of pain and self care correlated better with the clinical measures swollen and especially tender joints, while the self-reported mobility and self care corresponded to a greater degree with ARA functional class, walking time and grip strength. It is likely that the traditional clinical features measure two aspects of RA: swollen and especially tender joints measure active disease - which correlates better with pain and self care -, while walking time, grip strength and ARA functional class measure chronic changes - that correlate better with mobility and self care - (Bijlsma et al., 1990a). With regard to the specific correlations with the laboratory measures no coherence of the IRGL-scales and the laboratory findings, CRP and Thr, was found, as contrasted with ESR and Hb. An explanation for this phenomenon could be that CRP and Thr can be seen as acute reactive inflammatory parameters, while ESR and Hb react gradually. Finally, considering the fact that the correlations shown in table 2 refer to data of various kind (method of measurement, judge, behavioural measure and biomedical parameters) a correlation of .40 is reasonably high. On the other hand the coherence is not that high to assume that the IRGL measures exactly the same as the clinical and laboratory tests. The IRGL-scales for physical well-being claim to assess a broader scale of aspects than clinical and biomedical data alone would yield. These results support the criterium-validity of the scales for physical well-being.

Physical IRGL-scales	CLINICAL					LABORATORY			
	ARA	SJ	TJ	WT ^a	GS ^b	ESR	CRP	Hb	Thr
Mobility	-49 **	-04	-20	-37 **	38 **	-33 **	-20	23 *	-08
Self care	-41 **	-09	-37 **	-34 **	43 **	-28 *	-06	26 *	01
Pain	35 **	28 *	46 **	26 *	-35 **	31 **	18	-27 *	15

Pearson Two tailed *= $P < .05$, **= $P < .01$

ARA = ARA-functional class, measure for functional disability; SJ = nr. of swollen joints; TJ = nr. of painful joints; WT = time needed to wal 30 mtr.; GS = grip strength; ESR = sedimentation rate; CRP = C-reactive proteïne; Hb = haemoglobin; Thr = thrombocytes. ^a: N=69, ^b: N=70
NB. The higher the ESR, CRP and Thr values and the lower Hb-level, the more RA-activity is measured.

Table 2: Correlation between the physical IRGL-measures and the clinical and laboratory findings (N=71)

The validity of the scales for psychological and social well-being was shown in previous research with normal persons and/or psychiatric patients (Van der Ploeg et al., 1980; Zwart & Spooren, 1982; Van Dam-Baggen, 1989). The validity of these scales for patients with RA can be found in the lack of coherence between these scales and clinical and laboratory findings (Bijlsma et al., 1990a). However, further research of the validity of the psychological and social scales for patients with rheumatic diseases is necessary. To summarize, present findings are indicative of the reliability and validity of the IRGL as an instrument to assess health status in patients with rheumatoid arthritis.

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References

Anderson KO, Bradley LA, Young LD & McDaniel LK: Rheumatoid arthritis: A review of psychological factors related to etiology, effects and treatment. *Psychological Bulletin* 98: 358-387, 1985.
Bergner M, Bobbitt RA, Carter WB & Gilson BS: The Sickness Impact Profile (SIP): Development and final revision of a health status measure. *Medical Care* 19: 787-805, 1981.
Bijlsma JWJ, Huiskes CJAE, Kraaijmaat FW, Van der Veen MJ & Huber-Bruning O: Relationship between patients' own health assessment with clinical and laboratory findings in rheumatoid arthritis. *Journal of Rheumatology*, 1990a (in press).
Bijlsma JWJ, Oude Heuvel CHB & Zaalberg A: Meten van de kwaliteit van het dagelijks leven bij patiënten met reumatoïde artritis. *Journal of Rehabilitation Sciences*, 1990b (in press).
Cohen Sh & Wills TA: Stress, social support and the buffering hypothesis. *Psychological Bulletin* 98: 310-357, 1985.
Cornelissen GGJ: *Drempelvrees. Onderzoek naar de mobiliteit en sociale aspecten van reumatische aandoeningen*. Proefschrift, Erasmus Universiteit Rotterdam, 1984.

Dam-Baggen CMJ van: Sociale steun of het belang van de omgeving in een ander perspectief. *Gedragstherapie* 22: 37-51, 1989.
Fries JF, Spitz PW, Kraines RG & Holman HR: Measurement of patient outcome in arthritis. *Arthritis and Rheumatism* 23: 137-145, 1980.
Garssen B: *Sociale steun, een bijgewerkt verslag*. Intern Rapport, AZU, 1986.
Garssen B, Schreurs G, Oei TI & Zwart FM: Sociale steun en depressieve klachten. *Tijdschrift voor Psychiatrie* 27: 552-564, 1985.
Genest M: Coping with RA. *Canadian Journal of Behavioral Sciences* 15: 392-408, 1983.
Gran JT: The epidemiology of rheumatoid arthritis. *Monogr. Allergy* 21: 162-196, 1987.
Huiskes CJAE & Bijlsma JWJ: *Reuma*. Utrecht, Bohn, Scheltema & Holkema, 1989.
Huiskes CJAE, Kraaijmaat FW & Bijlsma JWJ: *De constructie van de IRGL: Een zelfbeoordelingslijst voor het meten van de invloed van Reuma op Gezondheid en Leefwijze*. Utrecht, Rapport AZU, 1988.
Huiskes CJAE, Kraaijmaat FW & Bijlsma JWJ: *De ontwikkeling van de IRGL: Een instrument om gezondheid te meten bij patiënten met reuma*. Gedrag en Gezondheid, 1990a (in press).
Huiskes CJAE, Kraaijmaat FW & Bijlsma JWJ: *Handleiding bij de zelfbeoordelingslijst Invloed van Reuma op Gezondheid en Leefwijze: De IRGL*. Lisse, Swets & Zeitlinger BV, 1990b (in druk).
Meenan RF: New approaches to outcome assessment: The AIMS questionnaire for arthritis. *Adv Intern Med* 31: 167-185, 1986.
Ploeg HM van der, Defares PB & Spielberger CD: *Handleiding bij de Zelfbeoordelingsvragenlijst ZBV*. Amsterdam, Swets & Zeitlinger BV, 1980.
Ritchie DM, Boyle JA, McInnes JM et al: Clinical studies with an articular index for the assessment of joint tenderness in patients with RA. *Quarterly Journal of Medicine* 37: 393-406, 1968.
Siegert CEH, Vleming LJ, Vandenbroucke JP & Cats A: Measurement of disability in Dutch RA patients. *Clinical Rheum* 3: 305-309, 1984.
Steinbrocker O, Traeger CH & Batterman RC: Therapeutic criteria in RA. *J American Medical Association* 140: 659-662, 1949.
Taal E, Jacobs JW, Seydel ER, Wiegman O & Rasker JJ: Evaluation of the Dutch Arthritis Impact Measurement Scales (DUTCH-AIMS) in patients with rheumatoid arthritis. *British Journal of Rheumatology* 28: 487-491, 1989a.
Taal E, Seydel ER, Jacobs J, Wiegman O & Rasker JJ: De Nederlandse Arthritis Impact Measurement Scales (DUTCH-AIMS): Bepaling van fysieke en psychosociale gezondheidsaspecten van reumatoïde artritis. *Gedrag en Gezondheid* 17: 69-74, 1989b.
Witte L de, Jacobs H, Horst F van der, Luttik A, Joosten J & Philipsen H: De waarde van de Sickness Impact Profile als maat voor het functioneren van patiënten. *Gezondheid en Samenleving* 8: 120-127, 1987.
World Health Organization: The first ten years of the World Health Organization. Geneva, WHO, 1958.
Zwart F & Spooren J: *Ontwikkeling van een zelfbeoordelingsvragenlijst voor depressie*. Utrecht, Intern Rapport, AZU, 1982.

APPENDIX. THE IRGL ITEMS

NR.	CONTENT
PHYSICAL	
	Time period: past month
Mobility	<p>1 I had to stay indoors most of the day because of my health.</p> <p>2 I spent most of the time sitting in a chair because of my health. I was able to:</p> <p>3 a. walk the stairs.</p> <p>b. ride a bike in the vicinity.</p> <p>c. walk (30 to 60 minutes).</p> <p>d. walk several stairs without a rest.</p> <p>e. ride a bike (30 to 60 minutes).</p>
Self care	<p>I was able to:</p> <p>4 a. button my blouse/shirt.</p> <p>b. tie my shoe-laces.</p> <p>c. open a previously opened pot.</p> <p>d. turn regular faucets on and off.</p> <p>e. take money out of an open purse in order to pay in a shop.</p> <p>f. cut meat.</p> <p>g. open a can.</p> <p>h. vacume.</p>
Pain	<p>5 During the past month I suffered from swollen (and eventually painful) joints.</p> <p>6 During the past month my arthritis caused pain.</p> <p>7 The joint-pain I suffered in the past month, I would describe as: very bad/bad/reasonable/little/hardly or no pain.</p> <p>8 During the past month I suffered from (very) severe pain because of my arthritis.</p> <p>9 If I compare the gravity of my arthritis during the past month with that of the previous months, there would be:</p> <p>– a worsening: more pain and/or swollen joints.</p> <p>– a stabilized situation.</p> <p>– an improvement: less pain and/or swollen joints.</p> <p>10 During the past month the duration of my morning-stiffness usually lasted for:</p> <p>– more than 2 hours.</p> <p>– 1-2 hours.</p> <p>– 30 minutes - 1 hour.</p> <p>– less than 30 minutes.</p> <p>– I had no morning-stiffness.</p>
PSYCHOLOGICAL	
	Mood: - depressive + cheerful
Mood	Time period: past week
11 a.	+ cheerful
b.	+ glad
c.	- depressed
d.	+pleased
e.	- gloomy
f.	+full of live
g.	- disheartened
h.	- low spirited
i.	- disconsolate
j.	+good humoured
k.	- sad
l.	+ happy
Anxiety	Time period: past month
12 a.	+ I feel pleasant.
b.	+ I feel contented.
c.	- I worry too much about unimportant matters.
d.	+ I am happy.
e.	- I am troubled by unpleasant thoughts.
f.	+ I feel safe.
g.	+ I am contented.
h.	- I have trouble letting go of certain thoughts.
i.	- I take disappointments too great-at-heart.
j.	- I become tensed and shaken when I think of my worries of the past period.

SOCIAL

Time period: past six months

- Nr. of neighbours 13. How many people in your neighbourhood you are so familiar with that you visit each other at home?
- Nr. of good friends 14. How many people you consider as good friends, that is to say, people with whom you feel at ease and who you can talk to about matters concerning yourself (you may include relatives).
- Potential support (P)
Actual support (A)
Mutual visits (M)
Restitem (R)
- (A) 15 a. I speak confidentially with others.
(A) b. Others come to me for support and advice.
(M) c. Friends and relatives visit me.
(P) d. When I am tensed or under pressure, there is somebody to help me.
(P) e. When I have a pleasant experience, there is someone I can share it with.
(P) f. When I am in pain, there is someone who supports me.
(R) g. I discuss personal problems with others.
(M) h. I visit friends or relatives.
(A) i. Others come to me with their personal problems.
(P) j. When I am sad there is someone to share it with.
(P) h. When I need help with tasks I cannot perform, there is someone to help me.

IMPACT OF RHEUMATIC DISEASE ON DAILY LIFE

Time period: in general

- Impact
- My rheumatic disease influences the following areas in my life:
- Activities 16 a. Work/Study
b. Household activities
c. Hobbies
d. Vacation
e. Leisure time
- Sexuality f. Sexuality
- Nutrition and Sleep g. Eating habits
h. Sleeping habits
- Relationships i. Relationship with friends and acquaintances
j. Relationship with relatives
- Partner-relationship k. Relationship with spouse/partner
- Family life l. Family life