Functional ability, social support and quality of life
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8 Conclusions and discussion

(Dirk Doeglas)

8.1 Introduction

This study is the result of a multicentre, multidisciplinary longitudinal European study, which was set up to explore the relationships between the physical, social and psychological components of the quality of life (QoL) construct in patients with Rheumatoid Arthritis (RA). Three general questions were studied. The first question was whether the instruments used in this study to measure functional ability (or physical restrictions, disability) and social support (supportive transactions as well as satisfaction with the support provided) had sufficient satisfactory psychometric properties, since these instruments occupy central positions in the models under study. The second question addressed in this study was on the effect of the physical component (functional ability) of QoL on the social and the psychological components of QoL. The social component of QoL was operationalized in two different ways. On the one hand, as the level of social support (both provided supportive transactions and satisfaction with the support provided). On the other hand, since social support stems from someone’s social network, as the extent of work disability as a result of RA was also used as an indicator of the effect of the physical component on the social component of QoL. The psychological component of QoL was operationalized as the level of depressive feelings. The third question that received attention in this study was about the main effect of social support on depressive feelings, and about the extent to which social support buffers the negative effects of stress. This stress is proposed to stem from the disability as a result of RA.

8.2 The main findings

8.2.1 Psychometric analysis of the instruments measuring disability (functional ability) and social support.

In the first part of this thesis, the psychometric properties of two instruments that have a very central place in the second part of this thesis are described: the Groningen Activity Restriction Scale (GARS) and the Social Support Questionnaire of Satisfaction with the supportive transactions (SSQS). The items of the SSQS run parallel with the items of the Social Support Questionnaire for Transactions (SSQT). The psychometric properties of the SSQT are described elsewhere (Suurmeijer et al. 1995). The first research question of this thesis was whether the GARS and the SSQS had satisfactory psychometric properties, to what extent the GARS and the SSQS are
invariant across countries, and what the sensitivity to change of the GARS is, as compared to the Health Assessment Questionnaire (HAQ), which is an often used instrument in research on rheumatology.

8.2.1.1 Measuring disability

Our studies have demonstrated that the GARS has good psychometric properties, which make this generic, i.e. non-disease-specific, instrument very useful for measuring disability in activities of daily living (ADL) and in instrumental activities of daily living (IADL). Secondly, the described studies showed us that the GARS is well suited for comparative research between different countries. For the countries involved in this study, the GARS was demonstrated to have a moderately strong and reliable first factor. Principal components analysis (PCA) showed that the variance accounted for was comparable for all four countries, both for its total scale and for its (ADL and IADL) subscales. Mokken Scale Analysis for polychotomous items (MSP) showed furthermore that the ADL and IADL items of the GARS form a strong unidimensional and hierarchical scale, which means that respondents with the same score meet the same problems on ADL and IADL activities. From the results from MSP, together with the correlations with other health status measures, such as the physical mobility subscale of the Nottingham Health Profile (NHP), the somatic symptoms subscale of the General Health Questionnaire (GHQ-28) or the Overall Evaluation of Health (OEH), can be learned that there is no statistical reason to use the ADL and IADL scales separately. Together with the fact that both subscales are strongly related (.79 -.86), we suggest to use the GARS as one scale.

 Probably due to its complicated manner of scoring, the psychometric properties of the HAQ were never published before. In chapter 3, it was shown that the psychometric properties of this RA disease-specific instrument are excellent and comparable to that of the generic GARS. With respect to the longitudinal results, the sensitivity to measure change, the GARS and HAQ both yielded a somewhat inconsistent result. The effect sizes in terms of standardized response means of both instruments obtained (much) better results for patients who improved, in contrast to patients who worsened in joint tenderness as measured with the Ritchie Articular Index (RAI). However, in terms of relative efficiency (RE), the GARS was found to be more sensitive to change for patients who improved, while on the other hand, the HAQ revealed better results for patients who deteriorated between T1 and T2.

Compared to the HAQ, the GARS appeared to be less sex-specific. On scale level, and on many of the separate items of the HAQ, women yielded significantly higher scores. These differences in sex
could be demonstrated on 11 items (55%) of the HAQ, compared to four items (22%) of the GARS. Three of these four items belonged to the IADL subscale of the GARS. Therefore, also sex differences could be demonstrated for this subscale of the GARS. The total scale of the GARS was not sensitive for sex differences. For this reason, the conclusion of this specific part of this study is that when the HAQ is used in scientific research, sex differences should be taken into account. Particularly based on its simple way of determining the scores of patients and on its lower sensitivity for sex differences, it was decided to use the GARS for the further analysis performed in this thesis, instead of the HAQ.

8.2.1.2 Measuring social support

In accordance with the expectations, chapter 4 confirmed that the factor structure of the SSQS ran parallel to the factor structure of the SSQT. Furthermore, when compared to the reliability coefficients of the subscales of the SSQT, reported elsewhere (Suurmeijer et al. 1995), the reliability coefficients of the SSQS were even better. The Simultaneous Components Analysis (SCA) revealed, first, the somewhat problematic character of the Daily Instrumental Support (DIS) subscale. The reliability coefficient of this subscale for all countries together compared unfavourably to the rather satisfactory results of the other subscales. Also for Norway separately, the DIS subscale demonstrated poorer results. However, these results with respect to the DIS subscale of the SSQS are in line with the results for this component of the SSQT.

Secondly, SCA demonstrated that the other four subscales of the SSQS were invariant and stable across countries, which makes the SSQS as well as the SSQT suitable for international comparative research. Standardized regression coefficients have demonstrated that support satisfaction was more relevant in explaining health-related QoL, than supportive transactions. This result confirms the theory that social support can, or even must, be split into a component measuring supportive transactions and a component measuring the satisfaction with the supportive transactions provided. It can also be argued that, since social supportive transactions are less important for the assessment of quality of life, only social support satisfaction can be measured. However, since the items of the SSQS are directly connected to the items of SSQT, the SSQS items cannot be used separately. Besides, for other reasons, it may be important to know what the level of supportive transactions is on which the level of satisfaction is based.
8.2.2 The effect of the physical component of quality of life on the social and psychological component of quality of life.

The second research question that was dealt with in this thesis was twofold and formulated as: what is the impact of the physical component of QoL on the social component of QoL (question 2a) and what is the impact of the physical component of QoL on the psychological component of QoL (question 2b)? The effect of the physical component of QoL on the social component of QoL was studied in two ways. First, the extent of work disability of patients with early rheumatoid arthritis was investigated. The extent of work disability gives important information on the social component of QoL. The colleagues at work belong to one’s social network and can be an important resource for the provision of social support, and, more generally, having a job indicates to what extent someone has access to valued resources and how one is attached to life. Secondly, the effect of the physical component of QoL on social support (supportive transactions and satisfaction with the support provided) itself was investigated. Finally, the effect of the physical component of QoL on the psychological component of QoL was studied by investigating the relationship between functional ability and depression. Before the results with respect to the second research question are discussed, first the erratic pattern of RA will be briefly discussed.

8.2.2.1 The erratic pattern of RA

The present study clearly demonstrated the erratic pattern of early RA, which has also been described by others (Suurmeijer et al. submitted 1, Wolfe et al. 1991, Zeben et al. 1993, Ward 1993, Young 1995). On average, the functional ability of the patients hardly changed between T1 and T4, while on the individual level extensive changes were encountered. The present study also showed that whether (or not) one improves or deteriorates in functional ability largely depends on the (original) level of functional ability from which this improvement or deterioration resulted. This means that if change scores in functional ability are to be related to other measures, it is imperative to consider the level of functional ability from which the changes originated as well. Furthermore, patients who deteriorated in functional ability during one year had, in general, the best chances of improving in the subsequent year and vice versa. Some researchers have indicated that we did not use the most appropriate type of analysis for the data of our study. Therefore, it would be interesting to do multilevel analysis for longitudinal data and compare the results with our results (Snijders 1996, Snijders and Bosker 1999).
8.2.2.2 The effect of functional ability on work disability

In chapter five, it appeared that the extent of work disability was much larger in our sample than the figures mentioned in recent literature on this topic. Before the onset of their disease as defined by our inclusion criteria, only 41% (n=119) had a paid job. Sixty-two percent (n=74) of this group of 119 patients reported that after the onset they either worked less, were on sick leave or had quit their job, while 38% (n=45) stated that they were working without any restrictions. Only 12 patients had not encountered any changes at all in their ability to perform their jobs. Several other studies have demonstrated comparable figures of work disability. However, the disease duration in those studies was about 10 years, while the mean duration in our sample was much shorter: only 22 months. There are some possible reasons for these results. The patients in our study were only included when they fulfilled four out of the seven ARA criteria. These criteria are rather strict, and it might be a few years before patients meet four criteria. By the time the patients entered the study, the mean elapsed time since their first symptoms was 4.7 years. The use of less strict inclusion criteria would probably have led to a lower extent of work disability. In that case, patients are recognized as patients with RA (much) earlier while they have not yet quit their jobs. Another reason for the large extent of work disability found in our study could be the fact that the social security system of the Netherlands can be considered rather generous compared to the systems of other countries. As a result, the threshold for leaving one’s job may be lower in the Netherlands than in other countries. Another explanation could be found in the fact that, on the other hand, by the end of the eighties there was not full employment in the Netherlands. Many businesses had to reorganize, which meant that a large number of employees had to be discharged. In general, employees that are prone to illness have poorer chances of keeping their jobs or finding new ones in such circumstances.

Our study demonstrated that work-disabled patients scored worse on the Erythrocyte Sedimentation Rate (ESR), the RAI, Steinbrocker functional classes, the HAQ, and the GARS. These patients had also had surgical treatment more often and they were more often treated with Non-Steroid Anti-Inflammatory Drugs (NSAIDs). In this respect, work disability seems a logical consequence of RA.

8.2.2.3 The effect of functional ability on social support

Among other things, the effect of functional ability on social support (the social component of QoL) was studied in chapter 6 and 7 of this thesis. Before the result of the pilot study and main study are discussed, attention will first be paid to the similarities and dissimilarities between pilot study and main study.
Similarities and dissimilarities between pilot study and main study
The cross-sectional study of chapter 6 was based on the pilot data of the EURIDISS-project, while for chapter 7 longitudinal data of the main study were used. Although, the patients in the pilot and the main study were comparable on mean age and the proportion women/men, there are two important differences between the studies of chapter 6 and 7. Firstly, the disease duration of the patients in the pilot study was 8.2 years compared to 22 months in the main study at T1. Secondly, in the pilot study the daily emotional support (DES), problem-oriented emotional support (PES) and social companionship (SC) subscales of the SSQT were used, while in some of the analyses, a combination of the DES and PES subscale (DES + PES) was used. However, since we did not succeed in demonstrating the buffering effect of social support in the pilot study, and since chapter 4 demonstrated that satisfaction with the support provided (SSQS) seems to be more important in explaining health-related QoL than the supportive transactions, it was decided to use the SSQS in the main study. For these analyses, social companionship satisfaction (SC-SAT) and (as in the pilot study) a combination of the DES + PES satisfaction subscales were used. This combined subscale was called emotional support satisfaction (ES-SAT). Furthermore, the pilot study demonstrated rather poor results for both daily instrumental support (DIS) and problem-oriented instrumental support (PIS) subscales of the SSQT. The adapted version of the DIS and PIS subscale unfortunately did not lead to better results and were therefore not used in the analysis of chapter 7.

Results of the pilot study and main study
In general, it can be concluded that the relationship between functional ability and social support is indistinct. The only weak but significant relationship between functional ability and social support was found in chapter 7 for emotional support satisfaction (ES-SAT): greater functional ability is related to more satisfaction. The other social support satisfaction subscales were not related to functional ability, nor were changes in functional ability associated with either changes in emotional support satisfaction or changes in social companionship satisfaction. Neither did the pilot study succeed in demonstrating a significant relationship between functional ability and social-emotional supportive transactions, although a trend in this direction was noticeable.
Chapter 7 also demonstrated that the mean levels of satisfaction with the provided social support are very stable over time. As a result of this stability of social support and of the close social network members (household members and close family members) (Suurmeijer et al. submitted 2), there is only a weak relationship between functional ability and social support. Furthermore, an
increase in restrictions in functional ability seems to trigger (not significantly) some supportive transactions (chapter 6). Probably due to the fact that satisfaction with the support provided is an evaluation of both someone’s needs and the amount and type of the provided supportive transactions (which is a rather complex mechanism), such a relationship between functional ability and social support satisfaction could not be demonstrated.

8.2.2.4 The effect of functional ability on depression

The effect of the physical component of QoL on the psychological component of QoL was studied by investigating the relationship between functional ability and depression.

In the pilot study, the total GHQ-28 scale as well as its four subscales (somatic symptoms, anxiety and insomnia, social dysfunctioning, and severe depression) were used as indicators for the psychological component of QoL. In that study, only the severe depression subscale and the ADL subscale of the GARS were related to each other. It was therefore decided to use only this subscale of the GHQ as the indicator for psychological QoL in the main study, and to omit the other subscales of the GHQ from the analysis. Cross-sectionally, functional ability and depressive feelings appeared to be weakly (but significantly) related to each other: about .25, which applies for both the pilot study and the main study.

Furthermore, on the basis of longitudinal analysis, it was demonstrated that stable patients with either a high or a low level of functional ability were not confronted with changes in depressive feelings, and that the stable patients with fewer restrictions in functional ability were less depressed than stable patients with many restrictions in functional ability. Contrary to the expectations, not only the patients who deteriorated in functional ability demonstrated higher levels of depressive feelings, but also patients who improved between two points of measurement. Probably as a result, changes in depressive feelings appeared not to be related to changes in functional ability, for one-year intervals. All in all, it must be concluded that depressive feelings are not directly-proportionally related to the level of functional ability. The presumed fairly obvious relationship between functional ability and depressive feelings apparently does not seem to be that obvious at all. However, for the somewhat larger T1-T4 (3 years) interval, a moderate relationship (.20) could be demonstrated, while, compared to the other variables under study, also the change in functional ability was relatively important in estimating depressive feelings at T4.

An explanation for the fact that patients who improved in functional ability also demonstrate higher levels of depressive feelings can be found by introducing an intermediating variable: the level of uncertainty with respect to the course of disease and its consequences.
for the patient. Both patients who improve and who deteriorate in functional ability face changes in illness activity. Changes in illness activity (the erratic pattern of RA) result in more uncertainty and unpredictability as to the future course of the disease. As a consequence of uncertainty and unpredictability, the patient is not sure whether or not he/she will be able to perform certain activities next month. Next, depressive feelings may be aroused in both ‘change groups’.

8.2.3 The effect of the social component of quality of life on: 1) the psychological component of quality of life, and on: 2) the relationship between the physical and the psychological component of quality of life: the main and buffering effects of social support.

Finally, in chapter 6 and 7, the relationships between the physical (functional ability), the social (social support), and the psychological (depression) component of QoL were examined, and, in particular, the direct and buffering effect of social support. Theoretically, social support has two different effects on health or health-related quality of life. The first effect is called the direct or main effect of social support, while the latter effect is called the stress-reducing or buffering effect of social support.

8.2.3.1 The direct effect of social support on depression
In the pilot study, the direct effect of the supportive transactions (SSQT) was tested in a cross-sectional analysis and confirmed for daily emotional support (DES) and social companionship (SC). These two types of supportive transactions were negatively related to the total scale of the GHQ-28 and to its subscales, indicating that more supportive transactions were related to a better outcome in psychological QoL. In contrast, problem-oriented emotional support (PES) was positively related to depressive feelings, which means that more problem-oriented emotional supportive transactions were related to more depressive feelings. This result is in conflict with the assumption that social support has a direct or main effect on QoL, but can be explained as follows. When patients experience less psychological QoL, for example as a result of a decrease in functional ability, their need for (problem-oriented emotional) supportive transactions will increase. The members of one’s social network are in general sensitive to such requests, and as a result problem-oriented emotional supportive (PES) transactions will be triggered in case of problems (need). Thus a decrease in functional ability is related to more depressive feelings and both are related to more problem-oriented emotional support. Since it is available every day, daily emotional support is probably a more stable type of support, compared to problem-oriented emotional support and thus,
compared to PES, less easy to trigger. Therefore, the relationship between DES and depressive feelings is different from the relationship between PES and depressive feelings: more DES leads to fewer depressive feelings. Furthermore, when the social network of patients does not respond adequately to requested problem-oriented emotional support, it is expected that these patients will subsequently experience more depressive feelings than those patients for whom the triggering mechanism does work well.

In the main study, only the effect of social support satisfaction on depressive feelings was studied. To that end, three subscales were used, emotional social support satisfaction (ESS; which is DES + PES) and social companionship satisfaction (SC-SAT). Satisfaction with emotional support and with social companionship at T1 was moderately related to depressive feelings at T1 and T4: more satisfaction coincides with less depression. As shown by the results of a regression analysis, emotional social support satisfaction at T1 appeared to be an important factor to assess depressive feelings at T4, which is also a clear indication of the direct effect of social support satisfaction on depressive feelings. Change scores in social support satisfaction could not be demonstrated to be related to changes in depressive feelings.

With respect to the direct effect of social support, the general conclusions of this thesis can be summarized as follows: daily emotional support and social companionship could be demonstrated to have a direct effect on QoL, while for problem-oriented social support this effect could not be demonstrated (chapter 6). Furthermore, satisfaction with the support provided had a stronger effect on QoL than the transactions provided (chapter 4).

8.2.3.2 The stress-buffering effect of social support

An important goal of the present study was to demonstrate the main and the buffering effects of social support. Theoretically, the presumed buffering effect is thought to be correct, although, until now, only a few studies (of the hundreds on the effects of social support) were able to demonstrate this buffering effect of social support in cross-sectional settings (Jose et al. 1998, Villeneuve et al. 1992, Kessler et al. 1992). In the present longitudinal study, the buffering effect of social support was investigated by computing interaction terms between the level of satisfaction with the social support provided and functional ability. Subsequently, the significance of these interaction terms was tested in a regression analysis. Applying this method, no studies with a longitudinal design have succeeded in demonstrating the buffering effect of social support. In the pilot study, interaction terms between the (I)ADL subscales of the GARS and the DES, PES and SC transactions were computed. However, a buffering effect could not be demonstrated by means of these interaction terms. In the longitudinal
main study, support satisfaction was used to compute the interaction terms. But the buffering effects of social support satisfaction were also rather disappointing. Using T1 scores and T1-T4 changes scores to assess depressive feelings at T4, no significant buffering effects of social support were found. Using another time interval (any of the 6 possibilities) did not lead to better results; only two significant effects (out of 12 possible effects) were found in six different analyses. In this respect, the results of this study are in line with the majority of studies on social support that did not succeed in demonstrating the buffering effect by means of significant interaction terms in a regression analysis. What explanations can be found for the fact that the stress-buffering effect again failed to show up? One of the possibilities is that the time intervals between the waves of data collection were not long enough. Using longer time intervals of, for example, 10 years will certainly lead to a decrease in mean level of functional ability (as a result of the progressive character of RA) and also to greater differences between patients, resulting in a larger standard deviation. Patients with a lower level of functional ability will have to face more problems in their daily life. But this does not necessarily mean that those patients also have to cope with more stress and, subsequently, with more depressive feelings. In biological terms, stress is defined as the non-specific reaction of an organism on every stimulus that threatens the integrity of that organism (Seley 1956). Such a threatening situation is accompanied by feelings of anxiety, tension, alertness, depression and guilt, as well as with changes in locomotion and in mental functions (Lazarus 1966). The personal situation does not change from one day to another but little by little. And people have the ability to adapt themselves to problematic (threatening) situations in order to prevent negative consequences. This could mean that the problems that the patients have to face as a result of their disease, will not become too substantial and that the encompassing level of stress will not become too high, making it possible for social support to buffer its negative consequences. Therefore, perhaps more attention should be focused on the several different coping mechanisms of patients and on the relationship between coping and social support (McColl et al. 1995). Social support is perhaps more important as coping assistance, than for its buffering capacities (Thoits 1986). Furthermore, some patients will find better ways to cope with their disease, while others don’t and continue to suffer from the burden of their RA.

8.3 Methodological issues
8.3.1 Study design and data collection

The EUropean Research on Incapacitating DIseases and Social Support (EURIDISS) was designed as a multicentre, multidisciplinary and longitudinal European study, in which several countries
participated. Before the study started in 1990, a thorough study design was developed, in which the sampling procedure and the collection of data were carefully determined and described. To be included in the study, patients had to fulfill a number of inclusion criteria, and were excluded when they fulfilled any of the exclusion criteria.

Although the EURIDISS-project was worked out well and the data were accurately collected, some critical remarks can also be made. From our study on patients with RA, it appeared in the longitudinal analysis over the first four years of disease that only minor changes in mean scores in the physical, social and psychological domains of QoL could be traced, although quite large individual differences did exist. Before, in section 8.2.2.1, this phenomenon was already described, and called the erratic pattern of RA (Suurmeijer et al. submitted 1, Wolfe et al. 1991, Zeben et al. 1993, Ward 1993, Young 1995). Diseases with an erratic clinical course are more difficult to study than chronic illnesses with a clear beginning and clear evolution, although specific measurement and analysis procedures have been developed for handling this type of disease process, like the area under the curve (AUC) approach (Lydick et al. 1995). In this method, mean scores over larger periods of time are used in statistical analysis (for example the mean of the scores on T1 and T2). Such composite scores fluctuate less, and could subsequently yield clearer results. Furthermore, others have recognized different subclasses in chronic diseases, each with its own course of disease. One subclass consists of those patients with a transient type of disease (Pincus and Callahan 1994), while another consists of patients who have a severe type of disease course, which does not respond to conventional drug therapy (Young and Van der Heijde 1997). This is not only the case in RA, but in other chronic diseases, like multiple sclerosis, as well. Performing certain analysis over all patients could obscure interesting results. Unfortunately, there are no methods available to separate specific patients into different groups.

8.3.2 Psychometric analysis

In the psychometric part of this study, Simultaneous Components Analysis (SCA) was used in order to test the invariance of components across countries. To this end, the results of the separate Principal Components Analysis (PCA) per country were compared to the overall result of SCA. One of the criteria in this analysis is that if the explained variance in the separate samples by the PCA is much larger than the explained variance found by the simultaneous component analysis (SCA), the idea of common components has to be rejected. On the other hand, when the difference between the PCA’s and the SCA is rather small, one can conclude that the studied components are invariant across samples. However, what differences
have to be considered large or small is not clearly specified. In our opinion, the SCA program would gain by having clearer rules with respect to considering components across samples as invariant or not. Clearer rules with respect to what differences in explained variance should be considered invariant components would help the users of SCA to make more uniform decisions. Also, the SCA program would improve by creating some directives with respect to whether or not one should consider certain items suspect or incorrect.

8.3.2.1 The measurement of functional ability
The first version of the GARS was designed with four answer categories per item. These answer categories were: 1) yes I can do it fully independently without any difficulty; 2) yes I can do it fully independently but with some difficulty; 3) yes I can do it fully independently but with great difficulty; and 4) no I cannot do it fully independently. At the time the EURIDISS-project was designed, it was thought that patients with an incapacitating disease would often answer that they could not do (some of) the included activities independently (category 4). In order to create more variation in the answer patterns of the patients, it was decided in advance to enlarge the number of answer categories to five. To this end, the original answer category 4 was divided into two parts and recoded as: 4) no, I cannot do it fully independently, I can only do it with someone’s help; and 5) no, I cannot do it fully independently, I need complete help. However, the data collected during the EURIDISS-project demonstrated that this extension was not really useful in the first years of RA. Due to the fact that the patients were not yet troubled by many physical restrictions, answer category 5 was seldom ticked, thus the expected increase in variation did not occur. In the performed analysis, the answer categories 4 and 5 were combined again to one category. For other patient groups with more profound physical restrictions, the use of five answer categories may still be recommended.

Because of the rather complex way of allocating scores to patients, the psychometric properties of the HAQ have not been studied before. In normal use, the 20 HAQ items result in scores on eight different domains. Subsequently, the HAQ score is computed from these eight domain scores. By considering the 20 items of the HAQ as single items, instead of items belonging to one of the pre-determined eight specific domains of which the HAQ consists, the present study has shown that the HAQ (scored in this way) has excellent psychometric properties. Therefore, we think that there is no reason to use the separate domains of the HAQ any longer, and we would suggest computing HAQ scores by just adding up the (20) item scores and dividing this score by 20. This is a much easier way to
allocate the HAQ scores and less prone to mistakes. The HAQ and the GARS are strongly related ($r=.83$) and have proved to have very good psychometric properties, which make them both suitable for psychosocial research.

8.3.2.2 The measurement of social support

In the present study, two related instruments were used for the measurement of social support. The SSQT collects information about the provided supportive transactions in various domains of social support, whereas the SSQS collects information about how satisfied the receiver is with these provided supportive transactions. The psychometric study revealed that the SSQS had less suspect (items that load on 2 components) or incorrect (items that load on a wrong component) items, compared to the SSQT. Also, the reliability coefficients for each of the components (subscales) were somewhat higher compared to the coefficients for the subscales of the SSQT. A reason for the somewhat better results of the SSQS can probably be found in the fact that all SSQS items deal with one single property: being satisfactory (sufficiently) supported or not. The SSQT, on the other hand, inquires about several different types of transactions on five different domains of support, which is less unequivocal than the entity of the SSQS.

Furthermore, the two subscales measuring instrumental support (daily instrumental support, or DIS, and problem-oriented instrumental support, or PIS) yielded poorer results in our study. Especially the psychometric properties (Cronbach’s $\alpha$) of the SSQT for these two subscales were poor, but also the properties of the SSQS with respect to DIS and PIS were clearly less (about .60) compared to these figures for DES, PES and SC (about .80). There are several reasons that could explain the rather poor performance of the two instrumental subscales. One reason is that one of the SSQT items of the DIS subscale (item 17) for some countries loaded on the PIS component. This could be an indication that the theoretical distinction in a daily type and a problem-oriented type of instrumental support is not quite clear. For emotional support, such a distinction in everyday support versus crisis support makes sense. A daily hug is something different from being reassured in case of need. But for instrumental support such a division is less clear, since instrumental support (both daily and problem-oriented) is only provided in those instances in which there always exists some kind of problem, how slight it may be. In this respect the DIS and PIS items should be more or less interpreted as two ends of the same continuum. Finally, it should be noted that the PIS in the main and pilot study differed somewhat, since the PIS component achieved rather poor results in the pilot study. It was, therefore, decided to adjust these items for the main study. The result was that in the final questionnaire, the PIS items actually asked for perceptions (‘if necessary’) while the other
subscales asked for the actual number of transactions. Based on these results, we can conclude that the DES, PES and SC subscales of the SSQT and the SSQS have good psychometric properties and are suitable for psychosocial research, while the instrumental support subscales need to be reconsidered.

8.4 Conclusions

What did the present study teach us about the psychometric properties of some of the instruments used, and the interrelations between the physical, the social and the psychological component of quality of life (QoL)?

1. The GARS has been shown to have very good psychometric properties, while the total scale and its components (subscales) appeared to be invariant across countries. Therefore, the GARS is suitable for international comparative research across countries.

2. The GARS proved to be sensitive for measuring change and little or not susceptible to sex differences. It can thus also be used in longitudinal studies.

3. Until now, the psychometric properties of the Health Assessment Scale (HAQ) were unknown. This study has demonstrated that the HAQ can be considered a very reliable instrument for the assessment of functional ability in Rheumatoid Arthritis (RA), although sex differences should be taken into account.

4. The Social Support Questionnaire for Satisfaction with the supportive transactions (SSQS) has proved to have rather good psychometric properties, while its constituting components appeared to be invariant across countries. Therefore, together with the Social Support Questionnaire for Transactions (SSQT), the SSQS is suitable for international comparative research across countries.

5. The extent of work disability was as large as that found in other studies, but was established in the present study in a much shorter period of time.

6. In the early years of RA, mean scores on measures of physical, social and psychological QoL did not change much, although quite large individual variations did exist (the erratic pattern of RA).

7. Changes in functional ability between two points of measurement depended to a large extent on the level of functional ability from which this change occurred.

8. The relationship between disability and depression was weak, while only for a 3-year interval a weak relationship between changes in functional ability and changes in depressive feelings could be assessed: a decrease in functional ability coincided with an increase in depressive feelings. In contrast, for one-year intervals it appeared that, just like patients who deteriorated in functional ability, also patients who improved demonstrated higher levels of depressive feelings.
The utility of Simultaneous Components Analysis (SCA) would improve with clearer rules to decide whether components across samples are invariant or not and with clearer rules to decide whether or not items ought to be considered suspect or incorrect.

A relationship between functional ability and social support (either transactions or satisfaction) is weak and was only significant for social companionship satisfaction. Changes in disability appeared not to be related to Emotional Support Satisfaction (ES-SAT) or social companionship satisfaction (SC-SAT).

This study demonstrated the direct effect of social support on depressive feelings. For daily emotional supportive transactions (DES) and social companionship transactions (SC) more support was related to less depressive feelings. Furthermore, satisfaction with the support provided appeared to be more important in assessing QoL than supportive transactions. Cross-sectionally, emotional support satisfaction (ES-SAT) and social companionship satisfaction (SC-SAT) were moderately related to depressive feelings, while (ES-SAT) also appeared to be an important factor in assessing the level of depressive feelings later on in time.

This study could not provide any evidence for the buffering effect of social support.

8.5 Implications for future research

In the EURIDISS-project attention was paid to some of the relevant aspects of the interrelationship between the physical, psychological and social components of QoL. In her thesis on the relation between personality, social support and depression in rheumatoid arthritis patients, Krol (1996) paid particular attention to the interrelationship of personality, social support and depressive feelings. The focus of this study was more on the interactions of the physical and social component on the psychological component of QoL, i.e. on depressive feelings. In this respect, the study of Krol and this study complement each other, and the same data were used in both. However, much has yet to be done to make the picture of QoL of patients with RA complete.

In the first place, it would be interesting to perform a separate study in which both the results of Krol’s study and this study are combined. Krol found in her study that personality characteristics such as self-esteem and neuroticism are rather strongly related to depressive feelings, and furthermore, that the beneficial effect of social support partly operates through personality characteristics. This means that personality could be an important factor that deserves attention in the stress-buffering concept of social support. If the effect of social support depends on personality characteristics (for example because non-neurotic persons are more sensitive to supportive transactions or more satisfied with the support provided),
then these factors should be taken into account. On the other hand, as was stated before, also coping and differences in coping mechanisms probably will have an important effect on the QoL of patients with RA. Including coping and personality characteristics as a relevant factor, together with functional ability and social support in an assessment of psychological quality of life, could lead to a more complete picture as compared to the single parts of the study. Secondly, a large attempt was made in this study to demonstrate the buffering effect of social support. Despite all these efforts, we could only conclude that the buffering effect of social support had to be rejected for our sample of patients with RA. This is a rather disappointing conclusion, for which no clear explanation can be given. Theoretically, the buffering effect is a generally accepted mechanism and the data were collected in a careful and appropriate way. Why couldn’t we find any support for it in this study? As already mentioned before, perhaps the one-year intervals between two waves of data collection were too short, the erratic pattern deserves special methodological attention, or coping should be more taken into account. Perhaps it is not that socially supportive transactions are relevant in themselves, nor the satisfaction with the support provided, but particularly the availability of some important other, for example someone belonging to the close social network, in case of need. The presence or absence of social support could be more important than the actual number of supportive transactions or the extent of satisfaction. The difference between no support and a little support could be much larger than the difference between little support and much support. In this respect, a little support can already provide someone with quite extensive feelings of security (McKee and Vilhjalmsson 1986).

Also another EURIDISS study on QoL gave important clues for future research. Suurmeijer found that patients who scored high on risk factors, like pain and fatigue, demonstrated a worse outcome on all three domains of QoL, and that the impairment variables pain and fatigue were better predictors than were variables related to disease activity, like ESR (Suurmeijer et al. submitted 1).

From our results on the effects of support satisfaction (chapter 7), it appeared that many patients were not (or not completely) satisfied with the support that was provided to them. This dissatisfaction concerned not only social companionship, but daily emotional and problem-oriented emotional support as well. This implies that the patients are either provided with too little support or with the wrong type of support, or even with the right type of support but provided in the wrong way. Furthermore, emotional social support is often provided by the significant others of the close social network, like the spouse, children or other close family members. This could indicate difficulties in explaining and recognizing needs and desires from
both sides, or at difficulties in communication between the provider and the receptor of support. Better communication could lead to ‘better’ support, and, thus, to greater satisfaction with the support provided. Subsequently, higher levels of support satisfaction will at least have a positive effect on depressive feelings, but could perhaps also have some implications for demonstrating the buffering effect of social support. It would be interesting to evaluate the effects of communication training for both patients and their partners on their quality of life outcome. In this respect, the so-called ‘partner weekends’ for patients and partners of the Dutch Nationaal Reumafonds are worth mentioning.

The study on work disability yielded interesting insights with respect to both the extent of work disability in the Netherlands and to related factors. One of those interesting factors which needs some further research is the fact that, although the disease duration in the group with work disability and in the group without work disability is comparable, the time passed since the first symptom of RA showed up, was longer in the group without work disability: 4.0 versus 5.7 years. An explanation for this longer time since the first symptom of rheumatism showed up in combination with not getting work-disabled is perhaps that some patients face a slower course of disease and, therefore, have had more time to become adjusted to the burden of their disease. Since these different patterns of disease course are still not obvious, nor the factors influencing these courses of disease, more research on this topic is recommended.

A final remark with respect to future research concerns the patients who demonstrated improvements in functional ability. It was expected that such improvements would coincide with simultaneous feelings of reassurance, and, as a result, with less depressive feelings. However, our study showed that these patients also demonstrated higher levels of depressive feelings. As was mentioned before, an alternative or additional explanation for the decreased level of mental well-being in chronic patients could be found in the related degree of uncertainty with respect to the future course of the disease and its consequences. According to Wiener uncertainty prevails about whether: ‘1) there will be any pain, swelling or stiffness; 2) the area of involvement; 3) the intensity of the disability; 4) whether onset will be gradual or sudden; 5) how long it will last; and 6) how frequently flare-ups will occur’ (Wiener 1975). She distinguished two imperatives for the condition of variable uncertainty: the ‘physiological imperative’, which must be monitored for pain and disability, and the ‘activity imperative’, which must be acknowledged if one is going to maintain what is perceived as normal life. There is also often a lot of uncertainty about the course of RA. Some patients suffer from more illness activity more often than others, whose suffering may remain fairly constant for years.
Changes in illness activity result in more uncertainty and unpredictability in relation to the future course of the illness (Van Lankveld 1993) and in relation to others. As a consequence of uncertainty, the patient is not sure whether or not he/she will be able to perform certain activities the next day, next week, next month and so on, and it becomes more difficult to plan activities together, both for the patient and for the social network of the patient. When the transaction costs rise as a result of either a decrease in functional ability or an alternating course of disease (more uncertainty), a chronic patient will become less attractive as a social partner (Lindenberg 1990, Ormel et al. 1997). In other words, when the transaction costs exceed the benefits of supportive transactions, the number of these supportive transactions will decrease, which ultimately can lead to a decrease of the patient’s social network. In this sense uncertainty constitutes a restriction on the realization of valued objectives i.e. the realization, the achieving or the maintaining of a high quality of life. Thus, improving patients still can be uncertain with respect to their future and, thus, feel more depressive compared to patients that experience a rather stable course of disease. We would recommend paying more attention to the level of uncertainty of patients with chronic diseases in future research.

8.6 Practical implications

The outcomes of this research may be used for practical implications. The psychometric properties of the GARS was shown to be highly satisfactory, while also its capacity to measure change was good and it was not vulnerable for sex differences. As a result, we would highly recommend that researchers use the GARS in their study. Besides the excellent properties of the GARS, also most of the subscales of the SSQT and SSQS proved to have good psychometric properties. Although the instrumental support subscales (DIS and PIS) yielded less good results, we think that the DES, PES and SC subscales of both the SSQT and the SSQS provided researchers with useful information on this subject. For clinicians, the GARS is an excellent instrument to assess the need for home care. Although the study on work disability yielded a rather discouraging picture for patients with RA, it may also give some interesting starting points for coping with the risks of the disease for an occupational role. It appeared that 60% of the patients with a non-manual job were able to remain at work, while 50% of the patients with a manual job became more or less work-disabled. Furthermore, higher educated patients reported less work disability. Of course, compared to the less well-educated, the more highly educated are more likely to do office work, which requires less physical strength than manual jobs. But more highly educated patients are possibly also more capable of arranging other working conditions within their
jobs, and subsequently can maintain longer in their occupational role. Especially for the benefit of less highly educated workers we would recommend making information booklets available for patients with RA. Such a booklet could contain, besides some general information about RA, specific job related information on how to adapt either the work environment (special furniture) or work tasks. This information could be accompanied by a strong appeal to the employers to be cooperative where possible in case of need. As a result, patients could keep their jobs and remain employed as long as possible in a normal way.

Such information on job-related and other topics would be very helpful for patients. In the Netherlands, there are already a number of institutions that could provide such information to patients, for example, the coordination centre for chronic diseases (coördinatiecentrum voor chronisch zieken), the patient organisation for rheumatic diseases (reumapatiëntenvereniging), occupational therapists (ergotherapeuten), or a nurse especially appointed to counsel RA related problems (reumaconsulent), and, of course, by the rheumatologist who can inform and refer the patients to these institutions.

As stated before, our study demonstrated that many patients were not completely satisfied with respect to the support provided. This could point out differences in the perception of needs and desires with respect to supportive transactions between the provider of support and the receptor of support, leading to provision of supportive transactions which do not completely fulfil certain desires or expectations. Therefore, educational programs for chronic patients, such as patients with RA, should pay sufficient attention to how the patient and his or her partner and other close relatives communicate about what they need, desire and expect from each other (Taal 1997b). In this respect, communication training could be helpful for many patients and their partners.

To help patients with RA to cope with their disease, clinicians should also discuss aspects like the variability of the disease, raised levels of uncertainty (see also the discussion on uncertainty in section 8.5) and possibly related depressive feelings with their patients and family in time.