Consumer satisfaction, quality of life and distress with regard to social function and gender in severe mental illness*

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ABSTRACT

OBJECTIVE: The relationships between subjective satisfaction, distress and quality of life for severely mental ill patients with different functional levels and gender was investigated in a multi-center cohort, using a balanced mix of subjective and clinician ratings in an outcome-informed model for a clinical management based on shared decision making, “The Quality Star”. METHODS: Naturalistic data for 2552 persons, mainly with schizophrenia diagnoses, in long-term treatment and rehabilitation, were analyzed in a cross-sectional study. RESULTS: With increasing Social Function, rated with the split-GAF Disability/Functioning scale, the better were patients’ Satisfaction, subjective Quality of life and Perceived Global Distress. Women were more satisfied with the care but also more distressed. CONCLUSION: Main findings were in line with other studies. However, the gender differences are in line with some, but not with other, studies. This poses questions how patient factors, instrument constructs, and treatment, especially shared decision making, influence subjective reports.

Keywords: Consumer Satisfaction; Quality of Life; Perceived Distress; Schizophrenia; Social Function

1. INTRODUCTION

In addition to the continuous refinement of instruments for diagnosis and measurement of change in terms of psychopathology, development of instruments for meas-
ence of gender differences and functioning on subjective perceptions have varied between different studies. [13]. This raises questions if well adapted service models may stand a better chance to help, for instance if gender specific issue are targeted [14].

In research regarding the abovementioned complex relationships a great number of instruments have been used. However, from the clinical perspective, this multitude of alternatives may be one of the reasons why there is seldom wide-spread agreement on what instruments to use for practical monitoring in such an holistic perspective. In Sweden, a concept was developed, named “The Quality Star” [15,16], aimed to be a minimal platform for follow-up of psychiatric care in a multi-dimensional, holistic perspective using simple, global measures of generic nature. Instruments were chosen to be handy in clinical praxis, and fill the function to be a point of departure for a dialogue with users within the areas mentioned with an under-lying question “Where do we stand now?—How do we improve?”

With this perspective the choice of global instruments was made, illustrated in Figure 1.

A thorough research program at the Department of Psychology of Karlstad University has been launched with the purpose of (a) assessing the psychometric properties of the Quality Star and (b) investigating group differences within the cohort between patients with different background characteristics and with different intervention patterns, especially the Integrated Care Program (ICP), which during the last years has made great advancements in Sweden [10,17,18], and been tested in a number of different countries with various types of systems regarding health care and welfare [19]. Regarding psychometric properties of the Quality Star instruments basic works have been done by others regarding the split-GAF symptom severity and functional level scales [20], as well as the scale Burden for important other [21]. As part of the ongoing studies validation work has been published regarding the global, patient subjective instruments: Consumer satisfaction [22], Quality of life [23], and Subjective distress [24]. Further, a study dedicated to investigate group differences within the cohort [25] reported as one of the main findings that women were more satisfied with the health care and had better functioning compared to men.

The aim of the present study was to further investigate the relationships between the patient subjective measures of consumer satisfaction, perceived distress and quality of life for severely mental ill patients with regard to different functional levels and gender. The following questions are of special interest: “Are there differences regarding the patient subjective measures at different psychosocial functional levels?” “Are there gender differences in this respect?”

2. MATERIALS AND METHODS

2.1. Participants

Participants in this study were 2552 patients, 1340 men and 1212 women (52.5 and 47.5 percents respectively), where the Quality Star have been used at one or more occasions during a ten year period at psychiatric centers in 13 areas in Sweden, and where data were complete regarding professional and patient instruments. Patients were, by large, severely ill patients (SMI) in long-term treatment and support and rehabilitation schemes. Duration of illness mean was in the order of 17 years (SD about 12), based on data available from 77.9% of the cases. At first recording, which is used in this study, their mean age was 44.23 years (SD = 13.21), men somewhat younger than women (43.60 years of age and 44.93 respectively). The majority, 83.23%, had schizophrenia spectrum disorders (ICD codes F20-F29). Remaining patients had representations in particular from affective disorders (F3 chapter, 5.21%), anxiety states (F4, 2.70%), eating disorders (F5, 3.17%), and Personality disorders (F6, 2.12%).

2.2. Instruments

Consumer Satisfaction Rating Scale-self-rating version (ConSat-P). The original ConSat-P scale has been shown to have acceptable psychometric properties including acceptable internal consistency. Its use has been validated for schizophrenia spectrum disorders as well as for affective, anxiety and substance abuse syndromes [22]. The slightly changed version used by the Quality Star

![Figure 1](https://example.com/image1.png)

Figure 1. Graphic representation of global instruments in “The Quality Star” concept. Measures used for each dimension in parentheses. In addition to chosen quality dimensions, a representation of resource use is included in the bottom of the “star” by number of “days in care”, later to be specified by national treatment content codes. (Adapted from Ivarsson, Malm, Lindström & Norlander, 2010).
Network scale has 11 items in following domains: availability, atmosphere, continuity, information and participation, drug treatment, psychological and psychosocial interventions, result of treatment/care and trust in future well-being. All items are rated on a seven point scale with the format in principle +3 full satisfaction, +2 satisfied but with minor dissatisfaction, +1 More satisfaction than dissatisfaction, 0 equally satisfaction/dissatisfaction or indecisive, −1 to −3 formulated in a reciprocal fashion. Total score raw data are transformed to percentages where 0% is extreme dissatisfaction and 100% complete satisfaction.

Global Quality of Life scale (GQL). The instrument is a visual analogue scale [26]. The introductory question has the wording “How do you find your life situation right now?” and the anchor-points of the visual analogue scale (VAS) line are marked “Best possible life situation” and “Worst possible life situation”. The scale is a 10 cm line, thus giving a scale 0 - 100 mm, where 0 signifies the worst situation and 100 the best possible [27]. The GQL have been found valid for serious mental ill persons with acceptable psychometric properties [23]. Test-retest reliability was found satisfactory. Concurrent validity with the initial item of life satisfaction scale of MANSA, “Life as a whole”, was good (r = 0.85 and rho = 0.86). Content validity was clarified by associations with a number of validating measures. Healthy adults' ratings on the GQL, was found to be mean 76.0 (SD = 17.00).

Perceived Global Distress scale (PGD). The instrument is a visual analogue scale [26]. The introductory question has the wording “How much have you been bothered by your psychiatric problems during the last month?” and the anchor-points of the VAS line are marked “I have not experienced any psychiatric problems at all” and “My psychiatric problems have troubled me extremely much”. The scale is a 10 cm line, thus giving a scale 0 - 100 mm, where 0 signifies the worst situation and 100 the best possible [27]. The PGD scale has been found valid for serious mental ill persons with acceptable psychometric properties [24]. Test-retest reliability properties were found satisfactory. Concurrent validity with the last item of life satisfaction scale of MANSA, “Mental health” was (rho = 0.59). Content validity was clarified by associations with a number of validating measures. Correlation with depression index of Symptom Check List –90 (SCL90) was rho = −0.64. Healthy adults rated mean 89.55 (SD = 19.18).

Global Assessment of Functioning (GAF). With this instrument professionals rate global mental health from the perspective of psychic, social, and functional ability [28]. The scale has ten vignettes exemplifying symptom severity and psychosocial functioning to be used as reference in rating, each vignette representing successive 10-point intervals in the semi-quantifying in the total scale range 1 - 100. Rating 1 represents the maximum dysfunction and 100 best possible. In each vignette the first part exemplifies syndrome severity and the last part psychosocial functioning. GAF is a widely used scale and its psychometric properties are documented in several studies [e.g. 29-31]. The reliable use of GAF requires a conscious strategy for its use due to pit-falls in the basic instructions and guidelines [31-33]. The Quality Star network uses the split-GAF version, with separate ratings of symptom severity (GAF-S) and psychosocial functioning (GAF-F) [20]. The main measures taken by the network to obtain reliable results include basic education, monitoring of the database and calibration by participating centers against a set of video cases.

2.3. Design

The study was designed to clarify the importance of level of psychosocial functioning and gender for SMI patients’ subjective experience in the three patient subjective dimensions regularly monitored according to the Quality Star method. Thus, the dependent variables used were the scales for satisfaction with treatment and service (ConSat-P), the subjective global quality of life scale (GQL) and the perceived global mental distress scale (PGD) scales. The independent variables were gender (man/woman) and the Global functioning scale (GAF-F) according to the Split-GAF method. Four GAF-F categories were constructed based on the frequency distribution of data, considering that GAF-F scores 61 and above has been suggested as a level where recovery for serious mentally ill persons is well in progress, whereas GAF-F values below 30 is often seen as indicative of need for intensive treatment. As participants with GAF-F values 30 and below were judged too small in numbers, it was decided to include also the 31-40 GAF-F ratings in the most severe group.

Thus, the following four groups were created: GAF-F 40 and below, GAF-F 41-50, GAF-F 51-60, GAF-F 60 and above, named “Very low”, “Low”, “Intermediate”, and “Higher”.

2.4. Statistics

Descriptive statistics for model variables. The model was tested with Pillai’s MANOVA regarding psychosocial function and gender. Univariate F-test and Post hoc tests, and subsequently trend tests (Difference Custom Hypothesis Tests) were conducted.

2.5. Procedure

Decision to participate in the Quality Star network by the psychiatric departments include ethical conside-
Conclusions are presented after the basic measures. Concluding, a summary presentation (Figure 1) of all ratings is done and it is established what needs to be taken care of in the following client-directed outcome informed [34] review of the personal treatment plan. Entries to the local Quality Star software are transferred to the national database at intervals where participant identification is replaced by random identification.

3. RESULTS

The mean values for participants’ ratings on the subjective measures were: For ConSat-P total, mean 75.21 (SD = 14.67), for GQL 60.14 (SD = 25.34), and for PGD 61.46 (SD = 28.59). The mean values for GAF-S was 49.89 (SD = 11.92) and for GAF-F 50.10 (SD = 11.92). The total GAF score mean, based on lowest GAF-S or GAF-F value, was 47.27 (SD = 11.26). For mean values of the subjective measures divided by functional level and gender, see Table 1.

A Pillai’s MANOVA (4 × 2 factorial design) was conducted with Social Function (very low, low, intermediate, higher) and Gender (men, women) as independent variables, and consumers satisfaction (ConSat), global quality of life (GQL), and perceived global distress (PGD) as dependent variables. The analysis revealed significant effects for Social Function (p < 0.001, Eta2 = 0.027, power > 0.99) and for Gender (p < 0.001, Eta2 = 0.008, power = 0.98). However, the analysis did not show a significant main effect for the interaction Social Function × Gender (p = 0.273, Eta2 = 0.001, power = 0.62). Results from univariate F-tests regarding Social Function and Gender are shown below. For means and standard deviations see Table 1.

Table 1. Means and (standard deviations) for social function (very low, low, intermediate, higher) and gender (men, women) in regard to consumer’s satisfaction (ConSat), global quality of life (GQL), and perceived global distress (PGD).

<table>
<thead>
<tr>
<th>Function</th>
<th>Very low</th>
<th>Low</th>
<th>Intermediate</th>
<th>Higher</th>
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<tr>
<td></td>
<td>Men</td>
<td>Women</td>
<td>Men</td>
<td>Women</td>
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<tr>
<td>ConSat</td>
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<td>15.87</td>
<td>70.03</td>
<td>14.48</td>
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<td></td>
<td>73.35</td>
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<td></td>
<td>81.63</td>
<td>12.33</td>
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<tr>
<td>GQL</td>
<td>56.59</td>
<td>27.90</td>
<td>51.50</td>
<td>30.27</td>
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<td></td>
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<td>68.45</td>
<td>21.11</td>
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<tr>
<td>PGD</td>
<td>57.79</td>
<td>29.36</td>
<td>50.65</td>
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<td></td>
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<td></td>
<td>70.80</td>
<td>24.64</td>
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</table>
3.1. Social Function

Univariate F-tests showed significant effects for ConSat [F (3, 2544) = 42.19, p < 0.001], GQL [F (3, 2544) = 30.59, p < 0.001], and PDG [F (3, 2544) = 38.03, p < 0.001]. Post hoc testing (Tukey-HSD, 5% level) showed concerning ConSat significant effects between all the four groups according to a trend where the group with the higher function was the most satisfied with the care while the group with very low function was the least satisfied group. Similar pattern was found for GQL, where those with the best function scored more positively while those with the worst function score more negatively (even though there were no significant effects in regard to the low and intermediate groups) and for PGD (even though there was no significant difference between the very low function group and the low function group). Subsequently trend tests (Difference Custom Hypothesis Tests, 5% level) confirmed significant trends for all dependent variables indicating that the higher the social function, the higher would participants score on dependent variables.

3.2. Gender

Univariate F-tests showed significant effects for ConSat [F (1, 2544) = 7.02, p = 0.008] and PGD [F (1, 2544) = 10.79, p = 0.001]. Descriptive analysis ([Table 1]) showed that women were more satisfied with the care but also more distressed as compared to men.

4. DISCUSSION

The present study had two main results: (a) With increasing Social Function, as rated by professionals with the split-GAF-F scale, the better were patients’ Consumer Satisfaction, as well as their subjective Quality of Life and Perceived Global Distress; (b) Women, as a group, were more satisfied with the care but also more distressed as compared to men.

4.1. Differences in Subjective Dimensions According to Level of Social Functioning

In this study significant effects were found between all the four groups of Social function according to a trend where the group with the higher function was the most satisfied with the care while the group with very low function was the least satisfied group as measured with ConSat. We found no other studies describing associations between consumers satisfaction in relation to GAF-F apart from previous work from our group, where an Assertive Community Treatment (ACT) based CM program was compared with best usual praxis showing improved ConSat and GAF-F scores (whereas GAF-S, symptoms severity, and split-GAF total did not improve) [10].

Studies using the original GAF together with other satisfaction scales targeting similar conceptual domains as ConSat provide some support to our findings, judged with caution considering the complexity of satisfaction construct [12]. For instance, in a study with schizophrenia in a Swedish city an association between psychosocial functioning as measured by GAF and satisfaction with care was found, and its relationship with subjective quality of life, sense of coherence, satisfaction with daily occupations, self-directedness, interviewer-rated quality of life, psychopathology, and psychosocial functioning [35]. A study in Japan found patients with higher satisfaction amongst generally-insured, mainly other then schizophrenia patients with higher GAF, whereas no correlation was found for the less satisfied mainly schizophrenia patients [36]. An evaluation of the Lambeth Early Onset team, found GAF associated with consumer satisfaction, attributable to satisfaction with staff manners, perceived competence, willingness to listen, type of service offered, and belief that the treatment “is right for me” [37].

In the present study a significant trend was found for Quality of Life indicating that the higher the social function, based on GAF-F grouping, the higher would participants score on subjective quality of life, even though there were no significant effects in regard to the low and intermediate functioning groups in univariate F-tests. In a previous study in part of the cohort modest correlation between GAF-F and GQL was found (rho = 0.18) [23]. This is in line with previous research suggesting that these dimensions might be independent and should be assessed separately [38].

The only other study found concerning mainly schizophrenia patients using GAF-F and a quality of life measure (Lehman Quality of Life scale), was a First-Episode Schizophrenia Scandinavian study, but no associative results were presented allowing comparison [39]. Studies that described changes with other quality of life measures together with GAF-F changes, but in other patient groups, also give some support to the use of GAF-F for categorizing social functioning [40,41].

As mentioned in the instruments section, the GQL was developed from the corresponding item in MANS and LQOLP, and GQL correlation with the initial item of MANS, “Life as a whole” was rho = 0.86, with the MANS-total sum rho = 0.66. With this in mind, findings in a study with schizophrenia patients at six sites within the UK that found a correlation between MANS and GAF-F of r = 0.36 seems in line with the present study [42]. This fairly low correlation in the two studies can be assumed to indicate a relatively weak association and be a reason why there was no significant effects on GQL in regard to the low and intermediate functioning groups in univariate F-tests in the present study. This is not disappointing. A modest association between quality
of life and social functioning on group level is precisely a reason why the Quality star network included the GQL in its follow-up system, to be a remainder that in individual cases subjective quality of life may often be perceived as low though other measures are good, or vice versa.

Thus, it should not be assumed that GAF-F social function ratings, as a rule, are strongly associated with subjective experience outcomes measures such as self-esteem or satisfaction with life [43].

In this study a significant trend for the perceived mental distress, using the Perceived Global Distress scale, was found, indicating that the higher the social function, based on GAF-F grouping, the better would participants score on PGD, even though there was no significant effects in regard to the “Very low” function group and the “Low” function group in univariate F-tests. In previous work it was shown that correlations between PGD and different subjective and objective measures varied but depressive features seemed to play an important role in patients’ construct of PGD [24].

The reliable use of GAF-F groupings for describing associations with distress also seems supported by reports by others in distress associated areas. Such reports are available regarding “Apathy” correlation with GAF-F [44,45]. SCL90R and GAF-F both improved following care at milieu therapeutic wards [41], a psychotherapeutic program with mainly borderline patients showed improvements in GAF-F, and ratings on Target Complaint (TC), a measure to provide information about the three major complaints that led to seek treatment [40]. Reports of distress related measures between patient groups with parallel use of GAF-F and are also supportive. Such reports include a reports regarding “self-certainty” for bipolar and schizophrenia patients [46], using the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI) for schizophrenia and mood disorder patient groups [47], narcissism using the Narcissistic Personality Inventory (NPI-21), self-esteem and “self-beliefs about ability to cope” using the Rosenberg Self-Esteem Scale (RSES) in acute ward patients [48], and results with The Generalized Self-Efficacy Scale in a milieu therapeutic wards study [41].

4.2. Differences in Subjective Dimensions According to Gender

A main result in this study was that women, as a group, were found more satisfied with the care but also more distressed as compared to men, whereas no difference was found regarding quality of life. The finding that women are more satisfied with the care than men is in line with other studies, for instance reported from Norwegian outpatient clinics within 33 health trusts [49], and from a psychiatric catchment area in south Rome, Italy [50]. However, yet other studies found no gender differences regarding satisfaction with care and service, for instance in the EPSILON project regarding schizophrenia in five European countries [51], and a study with a community mental health team in North Yorkshire, England [52]. A pilot study by Nysam (A Swedish network for development of Key Figures) using the Quality Star instruments, report a ConSat mean of 75 with small variations between diagnoses but no significant differences between men and women [53].

In a previous work in part of the present cohort it was found that women were significantly more satisfied than men with the provided care, according to scores on ConSat, during an entire six year period studied, than men, though both showed increasing tendencies [25]. As no major differences in patient characteristics between genders were evident, it was hypothesized that service factors may be part of an explanation. The service delivery model of most services participating in the Quality Start cooperation are devoted to case-management and ACT principles and several centers practices a developed form of shared decision making, in which the Quality Star method is integrated. The question was raised, if this program and service form may attract women more.

The finding in this study that women, as a group, were more distressed, according to scores on the PGD scale, as compared to men, (whereas the opposite was the case for consumer satisfaction) is in line with finding in the mentioned Nysam study [53]. PGD self-ratings in the present study was 61.46, whereas the total mean in the Nysam study was in the range of 63 - 67 for psychosis patients (with women slightly more distressed than men), in contrast to means 57 - 32 in other diagnostic groups, where women were particularly more distressed in the affective disorder groups then men.

In view of previously mentioned opinion that subjective measures tend to be largely influenced by mood [12] and that much of the feelings of being ill seems to be channeled via affective symptoms [54], the question could be raised if affective aspects of perceived distress are particularly detected with the PDG, as its construct was found strongly associated to depressive features [24]. Possibly women express more perceived distress amongst psychosis SMI patients through a depressive component. To clarify this further, it would be fit to, in the first place, explore this using MANSAs, reported on item level, together with relevant variables, as PGD is derived from the last MANSAs item “How satisfied are you with your mental health” for stand-alone use. Our literature search failed at this time to find such studies.

A final finding in this study was that there was no difference between men and women regarding perceived

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quality of life, measured by the GQL scale. Similarly, the previously mentioned Nysam study found no significant difference in this regard [53]. This finding is in line with, for instance, a pooled analysis of 16 studies (using MANS or LQOLP) to study factors influencing subjective quality of life in patients with schizophrenia and other mental disorders, where it was found that gender did not have an effect [55]. Likewise, using the LQOLP instrument, it was found in a study with schizophrenia patients in the Netherlands that gender was not related to general quality of life [56]. The referred works and others have elaborated on what other factors have major effect on quality of life. To clarify this further, it would, again, be fit to explore this using MANS or LQOLP, reported on item level, together with relevant independent variables, as PGD is derived from the first MANSA item regarding satisfaction with “Life as a whole” for stand-alone use.

4.3. Limitations of the Study

Although the four groups of functional levels were sufficient to show variations in subjective measures in the cohort of serious mentally ill, it might have been of certain interest to add subjective evaluations from patients below GAF-F 30 (where intensive care and service is often needed) and to add a separate analysis of the main diagnostic group of schizophrenia in the material.

4.4. Final Remarks

A secondary result comes out of the use in this study of the fairly new split-GAF Social Function subscale, GAF-F and its use for categorizing functioning into “Very Low” to “Higher” Social Function groups. Literature regarding split-GAF use is still limited. A search for reports using this instrument revealed 32 articles citing the main methods article [20]. Summarizing, none of the studies were found with a patient groups similar to the cohort in the present work allowing direct comparisons. However, the descriptions found of GAF-F differences between patient groups, and, in some cases, changes over time are judged supportive to GAF-F reliability allowing its use to discriminate between group levels and justify our GAF-F based subdivision into “Very Low” to “Higher” Social Function groups.

In the present study, there was a trend for all three subjective areas in our study, i.e. consumer satisfaction, subjective quality of life and perceived distress, to have higher ratings with increased levels of observed social function. It may intuitively seem plausible that the three subjective dimensions travel together in the same direction. The first study question regarding differences in subjective measures depending on functional levels, thus got a positive answer, and, it may be added, this was possible to demonstrate with the global generic measures used. The second question, regarding the influence of gender differences was also verified. The combined effect of functional level and gender on the patient subjective measures was however not shown on significant level. Bearing in mind that the study was carried out as a cross-sectional study and our familiarity with case-mix differences between centers and also reminding that, as exemplified from the literature in the preceding discussion, variations in levels of effects of gender and functional levels on different subjective measures has been noted by several researches, this result underline the importance of scrutinizing case-mix details before comparing between patient groups or services. As the present cohort can be expected to be fairly representative for schizophrenia dominated SMI specialized psychiatric care in Sweden, it might be suggested to standardize materials regarding gender and functional levels before at all comparing centers regarding patient subjective outcomes.

The questions must also be raised to what extent variations shown might be explained also by the constructs of the measures used. For instance, the PGD may possibly be sensitive to “mood” elements, and it merits further studies to ascertain such aspects in comparison with other constructs. Other possible explanatory factors to the variations are for instance duration of illness, syndrome severity, as well as service delivery elements, both in form and in contents. Further studies in the series of investigations with the Quality star cohort should address this, by adding such factors in group analyses.

For the basic aim of the Quality Star, to be a tool to support dialogue with the individual patient, the result support the importance of talking though the situation in a multi-dimensional perspective as it is obvious that the general tendency that though subjective measures tend to “travel together” there is important individual variations in this sense. Thus, we do agree with for instance Priebe et al. [57] in their suggestion that: “If one is to make use of subjective assessments for the planning and delivery of care and treatment one has to use different instruments.” In this sense The Quality star, with a balanced mix of user perceived and clinician ratings, is an outcome-informed model for a clinical management based on shared decision making.

5. CONCLUSIONS

The main findings, that subjective reports of satisfaction, quality of life, and distress are more positive the better rated functioning, were in line with other studies. However, the gender differences in these respects are in line with some, but not with other, studies. This poses questions how patient factors, instrument constructs, and
treatment, especially shared decision making, influence subjective reports. Basic common variables in all these respects are needed in routine care to facilitate service comparisons. The Swedish “Quality star” initiative is an attempt to support development in this direction. The present study indicated that the used global measures could be sufficient for overview group comparisons, and supports that further efforts should be made to develop the model regarding routine reporting of needed variables.

6. ACKNOWLEDGEMENTS

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