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Quality of life and need assessment changes in individuals with severe mental illness:

A 5-year follow-up study.

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Abstract

The present study is a 5-year follow-up study of patients with schizophrenia and mood disorders, who were patients on a day-clinic in Landspitali University Hospital, Reykjavik, Iceland for more than one year in 2008. In all, 47 patients fulfilled the criteria and were interviewed that year at a baseline. Their needs were independently rated by themselves and by their key-worker. The interview with the patients also included quality of life assessed by the Lancashire Quality of Life Profile (LQoLP) which includes the Rosenberg self-esteem scale.. Five years later, 30 of them also participated in this follow up study, but in the meantime the day-clinic had been closed tvo years before follow-up. Over the 5-year follow–up quality of life of the subjects had deteroriated (-0.28) although not statistically significant owing to the small sample size and they had more unmet needs (+0.4). At follow-up one third of the subjects reported that they had no reliable friend and quarter of them had no close friend. Quality of life correlated with few unmet needs to a minor extent and more strongly with the level of self-esteem.

Keywords: need assessment, quality of life, key workers, severely mentally ill and deinstutionalise.

Introduction:

The Mental Health Services at Landspítali, the National University Hospital of Iceland have changed much since the 1960's. The introduction of new and improved antipsychotic drugs enabled severely and chronically mentally ill patients to be discharged from institutions. The purpose of these changes was to increase individual independence with patients who had been in psychiatric wards for a very long time and providing them assistance and opportunity for living outside the institution (Óttar Guðmundsson, 2007). Another fundamental shift has occurred within the Mental Health Services in Iceland in the past four decades for patients with severe mental illness. Traditionally viewed as passive recipients, these individuals are increasingly considered to have a legitimate voice in evaluating the effectiveness of the services they use (Hansson et al., 2001).

In recent decades, increased attention has been focused on the need to develop patient-centered outcome measures for individuals suffering from long-term illness (Slade, 1994). In this framework, met and unmet needs can be differentiated. A met need occurs when the patient has a problem that is ameliorated through the help given. An unmet need occurs when the patient has a serious problem wheather or not any help is given (Slade, 1994). There has also been increased interest in assessing the quality of life of patients suffering from long-term mental illness when planning for these patients (Lehman, 1983). The concept normally refers to the sense of well-being and satisfaction experienced by persons with regard to their live (World Health Organization, 1997). It is commonly understood that the quality of life for an individual is determined by personal traits, the environment and subjective evaluation in different areas (Pinikahana, Happell, Hope and Keks, 2002).

The assessment of quality of life in schizophrenia is a complex and difficult task, underpinned by a culturally bound and ill-defined construct. Despite this, common findings are beginning to emerge from the literature. First, it is very clear that people with schizophrenia suffer a significantly poorer standard of living than others in the community. This finding has been replicated again and again since the work of Lehman (1983). Second, it is becoming clear the people with schizophrenia can validly and reliably report their internal experiences and perceptions. The work of Voruganti et al. (1998), was instrumental in dispelling the notion that asking people diagnosed with schizophrenia about their quality of life was a fruitless exercise. Third, the (often gross) mismatch between patient perceptions of quality of life and key worker ratings is no longer viewed as proof that such perceptions are wrong. On the contrary, subjective assessment is now understood to be its own gold standard. Key worker-rated and patient-rated information, and objective and subjective assessments are different constructs. As such, they should not cluster but, instead, should provide complementary information about the patient in question (Warner et al., 1998). Finally, an understanding of factors that influence subjective quality of life in schizophrenia is also emerging. It appears that variables that reduce quality of life are of two types: a) those which affect perception; and (b) those which alter expectation. Influences such as pain and depression act as cognitive distorters and alter perceived reality. Expectations of life are often reduced in schizophrenia as patients accommodate to adverse circumstances (Sainford, Becker and Diamond, 1996).

A handful of studies have been performed that compare the evaluation of the key worker and the patient. The results show mismatch between the two evaluations (Middelboe, Mackeprang, Thalsgaard and Christiansen, 1998). Furthermore, they demonstrate that key worker and patient give similar estimates for the number of needs but that patients find more needs unmet than the key worker (Slade, Phelan, Thornicroft and Parkman, 1996).

Psychiatric doctors have studied the health of Icelandic patients suffering from schizophrenia. Their results show that these patients are underdiagnosed and undertreated when it comes to diabetes II, hypertension and dyslipidemia. Obesity was also found to be more frequent among schizophrenic patients than the general public (Ólafur Sveinsson et al., 2012).

Páll Biering, Guðbjörg Daníelsdóttir and Arndís Ósk Jónsdóttir (2005) studied the attitude and experience of recipients of The Mental Health Services in Iceland towards quality of the services they had received. The majority was pleased with received service during their stay at the psychiatric hospital. However, a large group of subjects was unsatisfied with follow up and information channeling after being discharged.

The subjects of the present study attended a day-clinic of the Mental Health Services in Iceland for many years. The clinic specialized in follow-up for discharged patients from prychiatric intensive care wards. What differeniated the day-clinic from other wards in the Mental Health Services is that it was located outside of the two major hospitals, being co-located with two hundred apartments for the disabled in three interconnected buildings. The day-clinic was responsible for psychosocial rehabilitation of patients with severe and chronic mental illness. The majority of the patients resided independently in the same building (Guðrún Blöndal and Kristín Ólafsdóttir, 2007). At the baseline of the study, medium age of participants was 54 years and they had suffered from the illness for 23 years on average. Although Browne et al. (1996) have reported poorer quality of life in older people with schizophrenia, most observers report little effect of age on quality of life (Corrigan and Buican, 1995). Knight (2009) investigated the long term effect on quality of life between two age groups of long-term mentally ill individuals; “younger“ and “older“ in North England and found out that satisfaction with quality of life was more 14 years later with the old ones but less with the young ones.

A study performed in the Nordic countries (n = 408) used Lancashire Quality of Life Profile (LQoLP) to assess the quality of life experienced, while need assessment with Camberwell Assessment of Need (CAN) assessed the factual circumstances in the individual´s everyday life. That study showed LQoLP total quality of life was on the average 4.49 on a scale from 1 to 7 and unmet needs were on the average 2.6. The study showed that only two objective living conditions were associated with subjective global well-being a) to have a close friend and b) to have larger number of friends and relatives available in the social network. Of subjective factors, satisfaction with health and self-esteem explained the largest part of the variance (Hansson et al., 1999).

The present study used the same measuring devices as the Nordic one; LQoLP and CAN. At baseline of this study, LQoLP quality of life was on the average 4.77 and unmet needs 2.1 (Svavarsdóttir, Júlíusdóttir and Lindquist, 2014). Another Icelandic study with out-patients from the Mental Health Services (n = 90) showed that unmet needs were on the average 2.4 (Eiríksdóttir, 2009).

When re-evaluating policy and operation of Icelandic Mental Health Services, decisions were made to adapt policies from other countries with regards to serving patients and institutionalized mental care wards were closed. The mentally disabled should live in the community and receive services from the Mental Health Services when needed (Sveinbjarnardóttir and Thorlacius, 2014). The day-clinic, mentioned before, was closed in 2011 and subsequently, follow up for discharged patients was only performed at outpatients clinics or in the community and in hospital mental health teams.

De-institutionalization has led to prosperity for most patients even though many of them had been abandoned, homeless and without care, according to psychiatrists Eisenberg and Laurence (2010). Discharged patients with chronic mental illness (n =302) from Sundby Hospital in Sweden were tracked over a 14 year period. Homelessness, criminality, abuse, suicide and somatic illness increased markedly among them When de-instituionalization was shown to produce new problems, interest in new ways to support discharged patients was raised (Belfrage, 1994).

A study from Finland showed that patients with a chronic disease always had some unmet needs even though they were in different areas over time. The study also showed that the community mental health care system was able to actively treat patients with schizophrenia during the first few years, but when the illness lasted longer, the care system became uneffective (Salokangas, 1994).

In the 1990, the Swedish government started investigation on the care and social support of patients suffering from long-term mental illness. The investigation showed that outpatients displayed more personal integrity, while receiving less support. But they had a lower quality of life and less social structure than in-patients (Foldemo and Bogren, 2002). The goverment´s investigation resulted in a psychiatric reform in 1994 containing directives for better support for outpatients. The psychiatric reform also focused on the comparison between caregivers and gave economic support to new care systems (Belfrage, 1994).

So far, the effects of patients being discharged from mental care wards as a result of policy making in Iceland or restructuring have not been studied. The aim of the present study was to assess the manner in which the psychiatric reform in Iceland influenced patients suffering from long-term mental illness after they were discharged from the clinic in terms of need satisfaction and quality of life. A further aim was to see whether there were differences between how the key worker and the patients reported the patient´s needs. The effects of objective and subjective factors on quality of life were also studied.

Method

Design

The design was a 5-year follow-up study. The study group consisted of patients who had spent more than one year at the psychiatric day-clinic in Hátúni 10 at Landspítali University Hospital of Iceland in 2008, who were between 31 to 78 years, and fulfilled ICD 10 criteria for schizophrenia and mood disorders (Svavarsdóttir et al., 2014). They were all interwieved at the baseline between November 2008 and February 2009. In all 47 patients participated. The interviews were structured and performed by two interviewers and included the following scales: The Lancashire Quality of Life Profile (LQoLP) and Camberwell Assessment of Need (CAN). Within 2 weeks after the baseline interview, a key worker from the day-clinic was interviewed by the same researcher using a structured interview (CAN) to assess the patient´s needs.
The follow-up interview was performed between September 2013 and January 2014, by the same interviewers as performed the interviews at the baseline and using the same scales. At the follow-up 30 patients participated.

Instruments

Quality of life was assessed with LQoLP (Oliver et al. 1996). The LQoLP is a structured self-report interview to be administered by trained interviewers. It assesses objective quality of life and subjective life satisfaction in nine life domains: a) work; b) leisure; c) religion; d) finances; e) living situation; f) safety; g) family relations; h) social relations and i) health. General life satisfaction is a single question asked twice, at the beginning and end of the interview, and the two ratings averaged. LQoLP also includes a) a patient global assessment of quality of life (Cantril´s ladder) and b) an interviewer assessment of the individuals global quality of life, c) an affect balance scale, d) a self-esteem scale (Rosenberg scale) and e) a happiness scale. Objective quality of life and personal characteristics are assessed by categorical or continuous measures depending on the content of the item. Subjective quality of life ratings are made on a seven-point Likert-type scale. The LQoLP has been used in a number of international studies, and has been translated into several languages, including most of the Nordic languages. The LQoLP has shown satisfactory reliability and validity (Oliver et al., 1997; Hansson, Svenson and Björkman, 1998; Van Nieuwenhuizen, Schene, Boevink and Wolf, 1998).
Assessment of needs was investigated both among patients and key-workers responsible for the treatment of the patient, using the CAN interview (Phelan et al., 1995; Hansson, Björkman and Svenson, 1995). In the present study the Icelandic translation of the research version 3.0 was used. The CAN scale consists of clinical and social needs divided into 22 areas: a) accomodation, b) food, c) looking after the home, d) self-care, e) day-time activities, f) physical health, g) psychotic symptoms, h) information about condition and treatment, i) psychological distress, j) safety to self, k) safety to others, l) alcohol, m) drugs, n) company, o) intimate rela-

tionship, p) sexual expression, q) child care, r) basic education, s) telephone, t) transport, u)money and v) social benefits. In each of the 22 areas are four sections: a) the severity of need (no problem = 0, moderate problem = 1, serious problem = 2), b) the current help received from friends or relatives (none = 0, low = 1, moderate = 2, high = 3), c) support from social services and out-patient clinics has the same ratings as the previous item, d) the adequacy of help received and satisfaction with the help (no = 0, yes = 1).

Participants

In total, 59 patients from the psychiatric day-clinic in Hátún 10 at the Landspítali University Hospital of Iceland, were approached at baseline and the final sample included 47 patients.

The mean age of the study-group at the baseline was 54 years. The number of women who participated was 19 and 28 men participated. The mean duration of their phychiatric illness had been 23 years. When they were interviewed at the baseline all the patients lived in their own apartments and most of them (n = 37) lived in the same building as the clinic had residence. The key worker who was interviewed at the baseline had worked with the psychiatric patients for forty years.

At the baseline the whole study-group attended the day-clinic but three years later the clinic was closed. Two years after the clinic was closed the same study-group was approached. Of the 47 patients from baseline, 17 of them did not participate in the follow-up study for various reasons. Some had deceased (n = 6) few had so severe psychopathological status that they were not able to participate in the assessment (n = 3), one could not be contacted and some refused to be interviewed at follow-up (n = 7). The final sample consisted of 30 informants The National Bioethics Committee (13-051-S1) in Iceland and the Data Protection Authority in Iceland (2013030388VEL/--) approved the study and all patients gave informed consent to participate.

Statistical analysis

The statistical analysis program Statistical Package for the Social Sciences (SPSS) 20.0 was used in this study to analyse the data. Multiple stepwise regression was used to investigate associations between objective life conditions, clinical characteristics and subjective factors which was the dependent variable. The objective life conditions in the analysis included the following variables: a) age, b) sex, c) frequency of family contact, d) close friendship, e) reliable alliance with friend, f) contact with a doctor past year for physical illness or mental illness, g) psychiatric hospital admission past year. The clinical characteristics were the number of identified unmet needs according to CAN. The subjective factors used in the analysis were satisfaction with life in the areas of a) health, b) work, c) leisure, d) safety, e) social relations, f) finances, g) religion, h) family situation and i) living situation along with the average of two questions about general well-being.

Results

Objective living conditions, social and clinical characteristics

Of the baseline sample, 10 patients could not be interviewed. Of the remaining 37 available patients, assessment were conducted on 30 subjects (81%). Mean age at first admission on a psychiatric ward was 29 years but half of the patients were admitted before the age of 23. The ages of the 47 patients in the 2008 study ranged from 16 – 56 years at first admission. Mean duration of illness, measured as first admission to hospital, was 23 years and one third of the patients had been hospitalised during the past year.

The changes in characteristics of the samples and objective conditions between baseline and follow-up are shown in Table 1. At baseline 92% lived alone but at follow-up 80% lived alone, 10% had moved to nursing homes and 2% were homeless. Patients visited their families less often at follow up, 7% fewer visited their family a every month at follow up and 8% visited their family more seldom than on a monthly basis. Only 13% were working at baseline and five years later 8% were working. .At follow up 12% fewer patients had a close friend and 27% fewer had a reliable friendship (someone to turn to if needed). Contact with doctors both for physical and mental illness was mostly the same at baseline and follow up, but fewer had been hospitalized the last year at follow up.

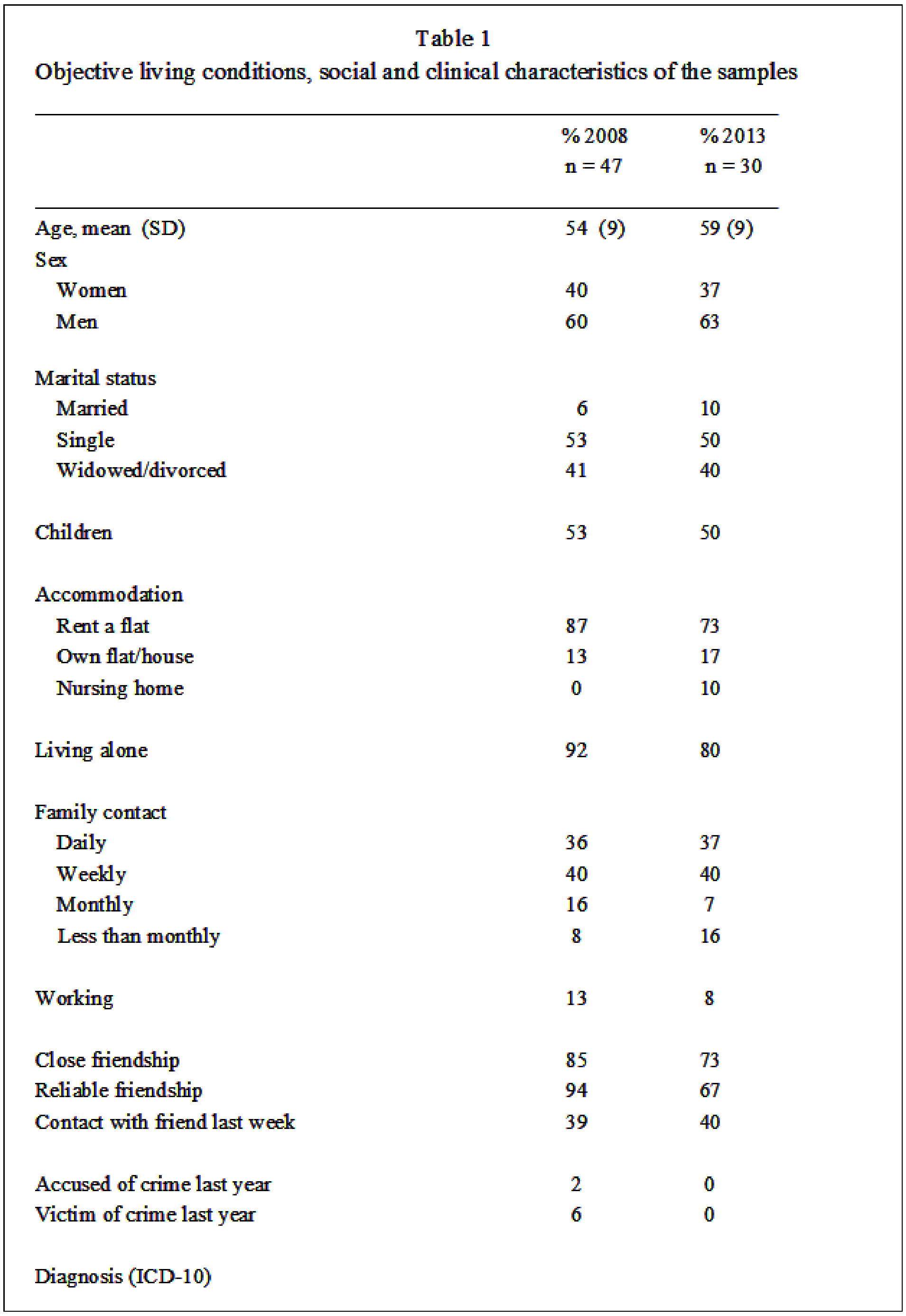

Table 1

Objective living conditions, social and clinical characteristics of the samples

	% 2008 n = 47	% 2013 n = 30
Age, mean (SD)	54 (9)	59 (9)
Sex		
Women	40	37
Men	60	63
Marital status		
Married	6	10
Single	53	50
Widowed/divorced	41	40
Children	53	50
Accommodation		
Rent a flat	87	73
Own flat/house	13	17
Nursing home	0	10
Living alone	92	80
Family contact		
Daily	36	37
Weekly	40	40
Monthly	16	7
Less than monthly	8	16
Working	13	8
Close friendship	85	73
Reliable friendship	94	67
Contact with friend last week	39	40
Accused of crime last year	2	0
Victim of crime last year	6	0
Diagnosis (ICD-10)		

Subjective quality of life

The results of the changes in satisfaction with subjective quality of life are snown in Table 2.

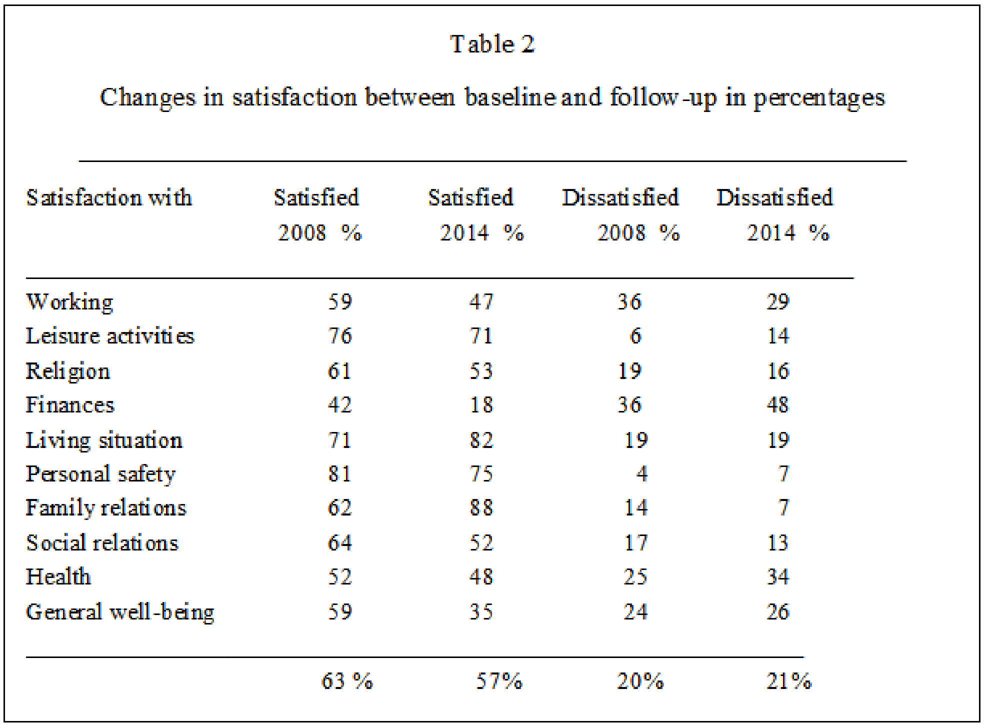

Table 2

Changes in satisfaction between baseline and follow-up in percentages

Satisfaction with	Satisfied 2008 %	Satisfied 2014 %	Dissatisfied 2008 %	Dissatisfied 2014 %
Working	59	47	36	29
Leisure activities	76	71	6	14
Religion	61	53	19	16
Finances	42	18	36	48
Living situation	71	82	19	19
Personal safety	81	75	4	7
Family relations	62	88	14	7
Social relations	64	52	17	13
Health	52	48	25	34
General well-being	59	35	24	26
	63 %	57%	20%	21%

Most subjects access their satisfaction poorer now than at baseline or 6% less satisfaction on the average. Only on two areas they assess their satisfaction better at follow up. Over a quarter, 26% were more satisfied with family relations at follow up and 11% were more satisfied with their living situation. Less satisfaction was regarding finances as 24% fewer were satisfied at follow up. The same difference is in their assessment on general well being, but there were 24% fewer that assessed their satisfaction with general well being at follow up than at baseline. On the whole, dissatisfaction with quality of life was the same between baseline and follow-up, but had changed between domains. Subjects assessed less dissatisfaction on four domains: a) work, b) religion, c) family relations and d) social relations but more dissatisfaction concerning: a) finances, b) general well being, c) health, d) leisure activities and e) personal safety. Nearly one fifth or 19% were dissatisfied with their living situation.

The results of the subjective LQoLP ratings, divided in 9 life domains, is shown in Table 3 and the changes between baseline and follow-up.

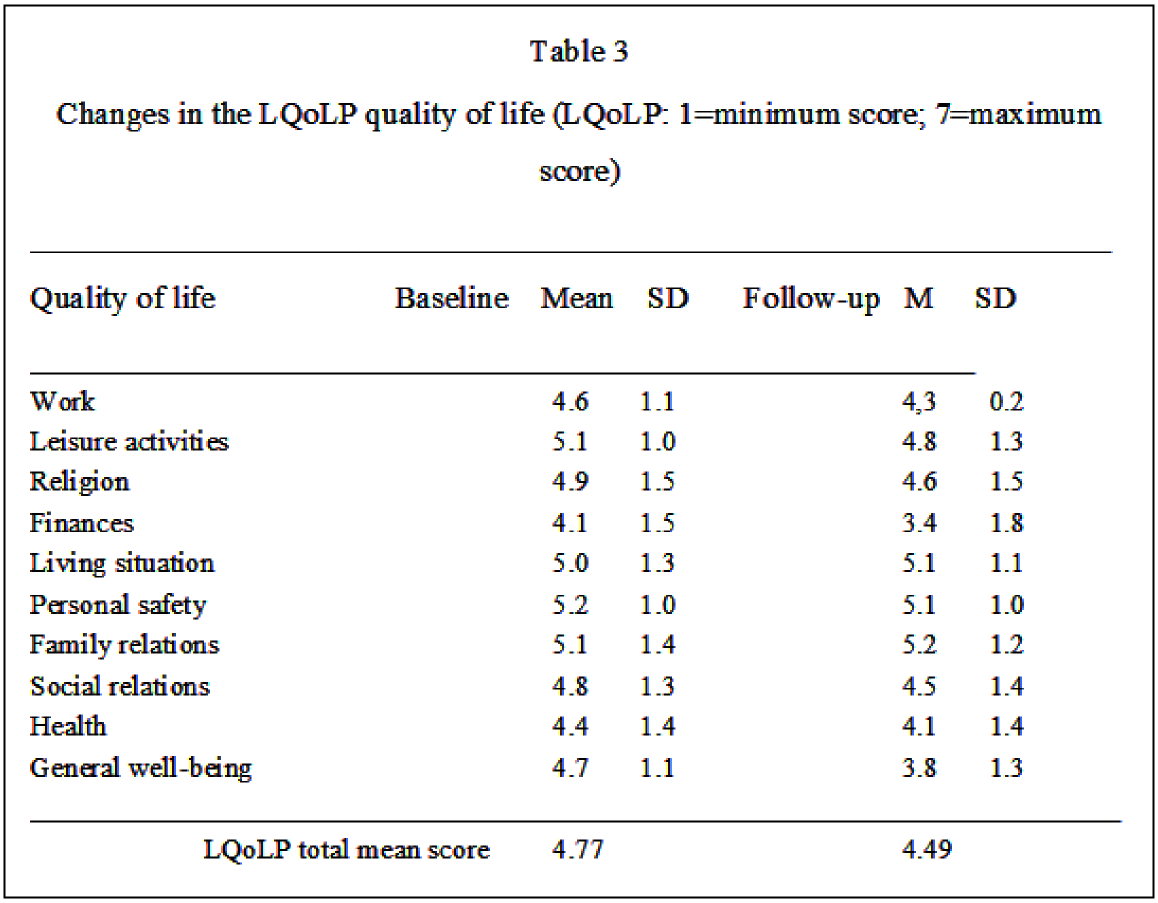

Table 3

Changes in the LQoLP quality of life (LQoLP: 1=minimum score; 7=maximum score)

Quality of life	Baseline Mean	SD	Follow-up M	SD
Work	4.6	1.1	4,3	0.2
Leisure activities	5.1	1.0	4.8	1.3
Religion	4.9	1.5	4.6	1.5
Finances	4.1	1.5	3.4	1.8
Living situation	5.0	1.3	5.1	1.1
Personal safety	5.2	1.0	5.1	1.0
Family relations	5.1	1.4	5.2	1.2
Social relations	4.8	1.3	4.5	1.4
Health	4.4	1.4	4.1	1.4
General well-being	4.7	1.1	3.8	1.3
LQoLP total mean score	4.77		4.49	

The subjects LQoLP total mean score is higher (+0.28) at baseline than at follow-up, although the differerence was not statistically significant, p = > 0.05, which might be because of the small sample size. On two domains their assessment at follow-up was higher: a) family relations (+0.1)and b) living situation (+0.1). Most difference from baseline to follow up, although not significant was on general well being (-0.9) p = > 0.05 and finances (-0.7) p = > 0.05.

Needs for care

As shown in Table 4, the total number of needs for care did not differ between baseline and follow-up.

Table 4

Changes in needs for care that occurred during the follow-up interval according to CAN

Domain	Agreement on need (n=47)		Agreement on need (n=22)	
	n	%	n	%
Acccommodation	36	76.6	17	77.3
Looking after the home	36	76.6	18	90.9
Food	34	72.4	12	54.6
Psychotic symptoms*	34	72.3	17	80.9
Physical health	29	61.7	17	81
Daytime activities	27	57.4	11	50
Company	24	44.5	9	40.9
Information	23	49.0	10	47.6
Psychological distress	23	49.0	15	68.2
Self care	15	31.9	8	36.4
Transport	13	27.6	9	40.9
Safety to self	12	25.5	4	19.1
Intimate relationships	11	23.4	6	27.2
Benefits *	9	19.6	3	15.8
Sexual expression	7	14.9	2	9.5
Money	7	14.9	6	30
Basic education	6	12.8	0	0
Childcare	2	4.3	0	0
Alcohol	2	4.2	0	0
Drugs	1	2.1	0	0
Telephone	1	2.1	1	4.5
Risk to others	0	0	0	0
Mean per individual	7.5		7.5	

Needs are listed after proportion of assessed need at baseline on each area, with the highest proportion on the top of the list.

At the level of the CAN domains, an increase was at follow-up in: a) physical health, b) psychological distress,c) looking after the home, d)money and e)transport. On the other hand there was decrease in: a) food, b) safety to self and c) daytime activities. Little changes were detected in other domains.

Table 5

Changes in unmet needs for care that occurred during the follow-up interval according to CAN

Domain	Unmet need (n=47)Baseline		Unmet need (n=22) Follow-up	
	n	%	n	%
Accommodation	1	2.1	0	0
Looking after the home	0	0	2	9.1
Food	2	4.3	2	9.1
Psychotic symptoms	8	17	2	9.1
Physical health	7	14.9	8	38.1
Daytime activities	5	10.6	6	27.3
Company	13	27.7	5	22.7
Information	17	36.2	3	14.3
Psychological distress	13	27.7	8	36.4
Self care	3	6.4	0	0
Transport	2	2.1	7	31.8
Safety to self	7	14.9	1	4.8
Intimate relationships	7	14.9	5	22.7
Benefits	5	10.9	4	20
Sexual expression	6	12.8	2	9.5
Money	1	2.1	0	0
Basic education	2	4.3	0	0
Childcare	0	0	0	0
Alcohol	1	2.1	0	0
Drugs	0	0	0	0
Telephone	0	0	0	0
Risk to others	0	0	0	0

Results of changes in unmet needs for care are shown in Table 5. In most domains the unmet proportion tended to be less favourable at follow-up, with the most clear-cut deterioration in the area of: a) transport, b) phys-

ical health, c) daytime activities, d) looking after the home, e) psychological distress, f) benefits, g) intimate relationships and h) food. Only four domains were favourable at baseline: a) information, b) self care, c) psychotic symptoms and d) safety to self. These results might indicate that no effective intervention had been applied to these needs after the clinic was closed.
The correlation of overall quality of life and unmet needs showed that a higher quality of life was assessed when there were fewer unmet needs , i.e. r = - 0.408 (p<0.01).

Subjectice versus interviewer assessment of global quality of life

The LQoLP scale includes a global well-being scale, Cantril´s ladder, and subjects mark their position in life on the 10 steps ladder from “could not be worse“ to “could not be better“. After the interview the interviewer answers also on a ten point scale his opinion on the subjects quality of life.
Table 6 shows correlation between the subjects assments and the interviewer with LQoLP total quality of life.

Table 6

Correlation in subjective assessment of patients and interviewer with LQoLP total quality of life

	Patients	Interviewer
Correlation with LQoLP total quality of life (4.77)	0.62**	0.43**

**= P<0.01

Higher correlation was in the patients assessment on their quality of life with LQoLP total score (r = 0.62) than in the interviewers assment and where they see their position in life. Patients assessed their position in life on Cantril´s ladder as higher (6.12) than the interviewer (5.7). Patient‘s assessment ranged from 1-10 or on the whole scale but the interviewer assessed their position in life from 2-8.

Needs for care identified by key worker and patients

Needs identified by key worker and patients and their agreement concerning the presence of a need, met needs and unmet needs is shown in Table 7.

Table 7

Identified needs by a key worker and a patient

	Patient (n = 47)	Key-worker (n = 47)
Met need	5.4	6.3
Unmet need	2.1	1.1
Total needs	7.5	7.4

From 22 different domains of needs, patients assessed that they have on the average needs in 7.5 domains and that is in accordance with the key worker‘s assessment (7.4). But they disagree concerning the number of met and unmet needs. A key worker assessed more needs fulfilled and fewer unmet compared with the patient‘s assessment. Furthermore a key worker and patients identify needs in different domains as is shown in Table 8.

Table 8

Needs for care identified by a key worker and a patients

Patient	%	Key-worker	%
Accomodation	76,6	Psychotic symptoms	94,8
Looking after the home	76,6	Accomodation	84,2
Food	72,4	Physical health	68,4
Psychotic symptoms	72,3	Company	65,8
Physical health	61,7	Looking after the home	63,2

The domains in table 8 are listed after the highest prevalence of a need and the highest is on the top. Among the five highest domains, both the key-worker and the patient assessed a) accomodation, b) looking after the home, c) psychotic symptoms and d) physical illness. On the other hand, according to patients 72.4% of them identified a need for assistance concerning food, but the key-worker identified only 32.5% patients that needed assistance because of food. The key worker identified 65.8% of the patients in need for social relations but only 44.5% patients identified need for that domain.

Table 9

Unmet needs for care identified by key worker and patients

	Patients agreement % unmet need		Key-worker agreement % unmet need
Information	36,2*	Company	21,1
Company	27,7	Intimate relationships	13,2
Psychological distress	27,7*	Self care	10,5*
Psychotic symptons	17,0*	Money	10,5*
Safety to self	14.9*	Looking after the home	7,9*
Intimate relationships	14,9	Transport	7,9*

There was also inconsistency in the identification of unmet needs with patients and key workers. According to the patients the highest prevalence of unmet need was found in the domains of a) information about treatment and condition, b) company, c) psychological distress, d) psychotic symptoms, e) safety to self and f) intimate relationships. The key worker identified also company and intimate relationships but beside that he identified a) self care, b) money, c) looking after the home and d) transport. Where the percentages is marked with *there is an inconsistency in the assessment of patients and the key-worker. The highest prevalence of unmet needs according to the patients was information about treatment (36,2 %) but the key-worker assessed only 2.3% unfulfilled needs on this domain. There was consistency in assessment of an unmet need for social relationships and intimate relationships with both parts. The key worker assessed psychotic symptoms as better taken care of, than patient. The same is valid for psychological distress and safety to self. The key worker assessed more unmet needs for a) self care, b) money, c) looking after the home and d) transport than the patients did. The results showed that the patients felt that they were not informed about their treatment but that it was not the case with the key worker. This raises the question, of how is the patient´s experience of receiving information and services different from the experience of those who provide it?

Predictors of quality of life

The correlation of overall quality of life and unmet needs showed that a higher quality of life was assessed when there were fewer unmet needs. Multiple stepwise regression analysis was used to investigate the associations between the number of unmet needs according to CAN , self-esteem according to the Rosenberg scale (which is included in the Lancashire scale) and the LQoLP total score, which was used as the dependent variable as shown in Table 10.

Table 10

Results of stepwise regression for influence of unmet needs and self-esteem on quality of life.

Variables	β SD in parenthesis	β SD in parenthesis	β SD in parenthesis
	Equation 1	Equation 2	Equation 3
Unmet needs β	-2.725* (0.129)	-1.522 (0.859)	
Self-esteem β		-.121** (0.033)	
Self-esteem β			-140* (0.131)
R2	0.17	0.33	0.31

*p<0,05 **p<0,01

The results of stepwise regression showed that the better self-esteem an individual had, the better quality of life the respondents considered themselves to be enjoying (β = 0,121 ** (p < 0,001). R2 = 0.33 (p < 0.001).

Discussion

The aim of this study was to investigate the influence that the closing down of a mental clinic in Iceland had on the quality of life and on the needs of the individuals who attended it. The group in this study represented patients who were treated by specialized mental health services and who received comprehensive treatment in settings that prioritised the continuity of care. Their mean age at baseline was 54 years and their duration of the illness was 23 years on the average and most of them had longitudinal service utilisation. At baseline 81% of subjects lived in the same building as the clinic resided. At follow-up 29% of them had moved away. Most of them had moved to nursing homes where they could get more services after the clinic was closed.

The patient‘s physical health had detoriated at the follow up. They visited doctors because of physical health more often than before, but the number of visits to doctors because of mental health was similar as before. Considerable difference was in the frequency of visits to psychiatric doctors in this study compared to the other Nordic Countries. Only 54% of the Icelandic participants visited a doctor because of mental illness the preceding year, compared to 81% of the Nordic participants (Hansson et al., 2003). This indicates that follow-up from psychiatric doctors is much better in the other Nordic countries than in Iceland. Other social characteristics of this group is that 53% of the Icelandic subjects had children but only 25% in the other Nordic countries. Possible explanation could be that all the subjects in the other Nordic countries had schizophrenia but only half of the patients in Iceland had schizophrenia. Another characteristic is friendship. At baseline 85% of subjects reported that they had a close friend but only 61% of the subjects in the other Nordic countries. Also 94% of subjects reported that they had a reliable friend (or someone they could turn to) but only 63% of the subjects in the other Nordic countries. At follow-up the subjects reported that they had fewer friends. Nearly three fourth or 73% reported that they had a close friend and 67% reported that they had a reliable friend. The Nordic study showed that friendship explained 4.9% of the variance in quality of life of the patients (Hansson et al., 1999). The difference in the subject‘s friendship in this study might lie in the closing of the clinic, since the subjects could always contact the clinicians who worked there and considered them to be their friends.

Six subjects from baseline had deceased and two deceased soon after the follow-up, four women and four men. The deceased women´s mean age was 69 years which is 14.7 years younger than among Icelandic women in general. Mean age of the deceased men was 60 years which is 17.7 years shorter than the mean age among the Icelandic men in general (Hagstofa Íslands, 2014). Reasearch on people that was discharged from mental hospitals from 1987-2006 in Danmark, Finland and Sweden (Laursen et al. 2011) showed that inspite of positive development, the men lived on the average 20 years shorter than other men and the women lived on the average 15 years shorter than than other women. The age at decease of women and men in this study seems to be in accordance with the results of this study that was conducted in Danmark, Finland and Sweden. According to the psychiatrists Eisenberg and Laurence (2010), deinstitionalization has led to prosperity for most patients, although many of them have been abandoned, homeless and without care. Studies suggest that continuity in medication, secure residence and access to appropriate social support in everyday life are the factors that contribute to the improvement and maintenance of quality of life for people with mental illness (Matthíasson, 2007). The results of this study indicate that there has not been a continuity in treatment with this group after the clinic in Hátúni closed down. The quality of life of the participants had deteroriated from baseline measure 4.77 to 4.49, two years after the clinic was closed. At baseline, their quality of life was measured as the highest for people with severe and long term mental illness compared to other nations. However at the follow-up their quality of life had declined and was among the lowest (Evans o.fl., 2000; Hansson o.fl., 2003; Slade o.fl., 2004; Schneider, Wooff, Carpenter, Brandon og McNiven, 2002). The subject‘s estimate of their quality of life had especially detoriated on the domains of general well-being, finances and social relations. They reported better quality of life on only two domains of ten; family relations and living situation. These results are in accordance with the long-term results of Knight (2009) in quality of life of “young long-term ill“ and “old long-term mentally ill“ in North England. Those results showed in five year interim, that there was less satisfaction with family relations and more satisfaction with health among the young ones, but the reverse was true for the old ones. In spite of reporting better satisfaction with family relation at follow-up than at baseline in this study, subjects report fewer visits to their family at follow up than before. But half of the subjects who had visited their family every month (n=16), visited the family more seldom than monthly at follow up. This raises the question about the nature of the relationship between patients and their relatives. These results might indicate that the relations with their families are not of the same nature as relations with peers. It is possible that relatives use comments about their lifestyle or surroundings that the patients dislike.

Ten subjects from this study participated in a qualitative study (Svavarsdóttir, Ólafsdóttir, Sturludóttir and Júlíusdóttir, 2012) where they reported that they felt they were not able to talk about their state of health and illness with other than people who had the same problem or clinicians that has earned their trust. They appreciated much to be able to discuss their matters with others who dealt with psychiatric illness and in environments where confidence was insured. This indicates that they prefer to communicate with other people with mental illness about their psychiatric illness. As a part of deinstitionalization the community has strongly emphasized that mentally ill people adjust to community. An example of that process is found in articles in magazines as "Geðhjálp" (Help for heople with mental illness) that is published by organization that work for people with mental illness. A number of articles have been puclished in that magazine concerning how bad it was for the disabled to live together in buildings like Hátún, but that was the residence of most of the subjects in this study. The severity in the opinions of Geðhjálp´s members can be seen in Indriðadóttir´s (2008) article, who was a member in Geðhjálp and former television reporter in Iceland. In that article she said that "the buildings for the disabled are examples of a storage room for the disabled. There disabled people are piled up in a sort of "ghetto." The service limited, finances limited. Slum for ill people." In this article is also Geðhjálp´s vision about accomodation for the mentally ill in the future. It is emphasized that it is necessity to stop using this building as for now and provide apartments in ordinary districts. One of the authors of this article was working at Hátún at that time and believes that this was well meant, but the inhabitants in Hátún seemed very hurt to hear and read about their homes in this manner.

Social worker´s experience of supporting mentally ill patients living in ordinary apartments among people that were not disabled, was on the other hand not always favourable. For example when something came up in the multi-apartment buildings, usually the first one to blame for it were the mentally ill. Also the inhabitants were frightened if their children were in the elevator alone with the mentally ill person. Thus the community seems not be ready to adjust to the diversity in behaviour of the long-term mentally ill and the mentally ill often don´t feel comfortable within the general community. What the inhabitants in Hátún appreciate the most is the solidarity that inhabitants show each other and there they don´t have the feeling that they are "different" as they tend to feel in the general community (Svavarsdóttir et al., 2012).
Studies show that there is a relationship between how mentally ill people assess their quality of life and how their needs are fulfilled (Bengtson-Tops et al., 2005; Hofer et al., 2004; Pinikahana et al.., 2002). The same relationship was found in this study, better quality of life was assessed at baseline and unmet needs were also lower at baseline than at follow up.

Subjects and their key worker assessed equal number of needs on the average, but they disagree concerning the number of met and unmet needs. Key worker assessed more needs fulfilled and fewer unmet, compared with the patients assessments. Furthermore the key worker and the patients identified needs in different domains. These results are similar to results of many studies that show little correspondence in their assessment (Middelboe et al., 1998). Furthermore, they demonstrate that key worker and patient give similar estimates for the number of needs but that patients find more needs unmet than the key worker (Slade et al., 1996). Subjective assessment of clinicians and patients reflect different points of view and should therefore not be identical (Warner et al. 1998), but rather give holistic information about each patient. For this reason the clinic in Hátún used the two evaluations, both the patient's and the key worker's. However their assessment of information on treatment and condition reflects big mismatch as the key worker assessed only 2.3% needs unmet but the patients assessed 36.2% of needs unmet. The results showed that the patients felt that they were not informed about their treatment but that it was not the case with the key worker. This raises the question, of how is the patient´s experience of receiving information and services different from the experience of those who provide it? A possible explanation for this mismatch is that when people are depressed, they have difficulty focusing and concentrating and that effects their ability to receive information. Patients in Eiríksdóttir´s (2009) study also assessed that information on treatment and condition were their most unfulfilled needs. These findings lead us to the view that clinicians should reconsider their methods in giving informations to patients, as the patients don´t seem to learn the informations they are given.

The one factor that most influenced quality of life in this study was self-esteem. Self-esteem proved to influence quality of life of these subjects more than number of unmet needs. A similar trend is found in the Nordic study of Hansson et al., (1999), but they investigated the relationship between social and clinical characteristics and total quality of life. It turned out that the subjects health explained the most part of the variance (36.5%) but other factors that explained the variance were self-esteem, depression and friendship. In an Italian study there was also a relationship between higher self-esteem and better temperament on one hand and general quality of life on the other (Ruggeri et al., 2001).

Friendship with another person is of great importance to most people and there has been much change among the former patients that attended the clinic. Now there are 12% fewer that state they have a close friend and 27% fewer state that they have a reliable friend (someone they can turn to). The explanation here is the closing of the clinic. At baseline when patients were asked about their friendship they often mentioned clinicians from the clinic to be both their close and reliable friend, that they could always turn to. Most of the subjects had received services from the clinic for a long period of time. These factors clearly seem to influence their detoriated quality of life at follow up because of the closing of the clinic.

Future Remarks

When quality of life and unmet needs as estimated by the subjects are compared between the years 2008 and 2013, the results show deterioration on some dimensions after the clinic was closed. A greater number of subjects estimated that more needs are unmet after the closing. Of special interest is the loss of friendship that subjects report at follow up because of the closing down of the clinic. Results strongly indicate that a continuum in service for this group has not been achieved after the clinic was closed and no effective intervention has been applied to address these problems. Furthermore it seems obvious that personality related factors such as self-esteem also play a role in the appraisal of subjective quality of life, which implies that factors like these are important to consider in clinical and social interventions for patients with serious mental illness in order to improve the quality of life for these persons.

References

Belfrage, H. (1994). Criminality and mortality among a cohort of former mental patients in Sweden. Nord J Psychiatry; 48:343-347.

Bengtsson-Tops, A., Hansson, L., Sandlund, M., Bjarnason, O., Korkeila, J., Merinder, L., o.fl. (2005). Subjective versus interviewer assessment of global quality of life among persons with schizophrenia living in the community: A Nordic multicentre study. Quality of Life Research, 14, 221-229.

Biering, P., Daníelsdóttir, G. and Jónsdóttir, A. Ó. (2005). Þjónustuþarfir geðsjúkra og reynsla þeirra af geðheilbrigðisþjónustu á Íslandi: Viðhorf, reynsla og félagsleg staða [Needs for service for the mentally ill and their experience of the mental health service in Iceland: Their attitude and social situation. Reykjavík: Geðhjálp and The Icelandic Red Cross. Retrieved March 12, 2014 from http://www.raudikrossinn.is/redcross/upload/files/innanladsstarf/gedfatladir_tharfir_jan06.pdf

Blöndal, G. and Ólafsdóttir, K. (2007). Bilið brúað milli bráðadeildar og hefðbundinnar göngudeildar þjónustu [Building a bridge over the space between acute and traditional out-patient service]. Geðvernd 36(1),31-37.

Browne, S., Clarke, M., Gervin, M., Waddington, J., Larkin, C. og Callaghan, E. (1996). Quality of life in schizophrenia; relationship to socio-demographic factors, symptomatology and tardive dyskinesia. Acta Psychiatrica Scandinavica, 94, 118-124.

Corrigan, P.W. & Buican, B. (1995). The construct validity and subjective quality of life for the severely mentally ill. Journal of Nervous Mental Disease, 183, 281-285.

Eisenberg, L. and Laurence, G. (2010). „Were we all asleep at the switch? A personal reminiscence of psychiatry from 1940 to 2010“. Acta Psychiatrica Scandinavia, 122(2) 89-102

Eiríksdóttir, M. (2009). Hagir og þarfir fólks með alvarlega geðsjúkdóma [Circumstances and needs of people with serious mental illness]. Unpublished masters dissertation: Univerity of Iceland, The Faculty of Nursing.

Evans S., Huxley, P. and Priebe, S. (2000). A comparison of the quality of life of severely mentally ill people in UK & German samples. International Journal of Social Psychiatry 46, 47-56.

Foldemo, A. and Bogren, L. (2002). Need assessment and quality of life in outpatients with schizophrenia: a 5-year follow-up study. Scand J Caring Sci; 16; 393-398.

Guðmundsson, Ó.. (2007). Kleppur í 100 ár [Kleppur for 100 years]. Reykjavík: JPV Publishing Hagstofa Íslands, 2014. Dánartíðni og ævilengd [Mortality and life expectancy]. Retrieved February 28, 2014 from http://www.hagstofa.is/?PageID=95&NewsID=8963

Hansson, L., Björkman and Svenson, B. (1995). The assessment of needs in psychiatric patients. Interrater reliability of the Swedish version of the Camberwell assessment of needs, instruments and results from a cross-sectional study. Acta Psychiatr Scand. 92, 285-93.

Hansson, L., Svensson, B. and Björkman, T. (1998). Quality of life of the mentally ill. Reliability of the Swedish version of the Lancashire Quality of Life Profile. European Psychiatry, 13, 231-234.

Hansson, L., Middelboe, T., Merinder, L., Bjarnason, Ó., Bengtsson-Tops, A., Nilsson, L et al. (1999). Predictors of subjective quality of life in schizophrenic patients living in the community. A nordic multicentre study. International Journal of Social Psychiatry, 45(4), 247-258.

Hansson, L., Vinding, H., Mackeprang, T., Sourander, A., Werdelin, G., Bengtsson-Tops et al. (2001). Comparison of key worker and patient assessment of needs in schizophrenic patients living in the community:a Nordic multicentre study. Acta Psychiatr Scand, 103, 45-51.

Hansson, L., Sandlund, M., Bengtson-Tops, A., Bjarnason, O., Karlsson, H., Mackeprang, T. et al. (2003). The relationship of needs and quality of life in persons with schizophrenia living in the community. A Nordic multi-centre study. Nord J Psychiatry, 57(1), 5-11.

Healy, K. (2005). Social work theories in context. Basingstoke: Palgrave Macmillan.

Hofer, A., Kemmler, G., Eder, U., Eddlinger, M., Hummer, M. og Fleischhacker, W. (2004). Quality of life in schizophrenia: The inpact of psychopathology, attitude toward medication and side effects. J Clin Psychiatry. 65 (7), 932-939.

Indriðadóttir, E. (2008). Annars flokks sjúklingar [Second hand patients]. Okkar mál, 10, 4.

Katsching, H. (1997). How useful is the concept of quality of life in psychiatry? Current Opini-on in Psychiatry. 10 (5), 337-345.

Knight, B. G., Karel, M. J., Hinrichsen, G. A., Qualls, S. H., and Duffy, M. (2009). Pikes Peak model for training in professional geropsychology. American Psychologist, 64 (3), 205-214.

Laursen, T.M., Wahlbeck, Westman, J., Nordentoft, M., Gissler, M., (2011). Outcomes of Nordic mental health systems:life expectancy of patients with mental disorders. The British Journal of Psychiatry. Retrieved March 4, 2014 from http://www.bjp.rcpsych.org/content/199/6/453.long

Lehman, A.F. (1983). The well-being of chronic mental patients:Assessing their quality of life. Archives of General Psychiatry , 40, 369-373.

Matthíasson, P. (2007). Samfélagsgeðlækningar [Community psychiatry]. Geðvernd 36(1), 13-19.

Middelboe, T., Mackeprang, T., Thalsgaard, A., Christiansen, P. (1998). A housing support program for the mentally ill: Need profile and satisfaction among users. Acta Psychiatr Scand, 98, 321-327.

Oliver, J., Huxley, P., Bridges, K., Mohamad, H. (1996). Quality of life and mental health services. London:Routledge.

Oliver, J., Huxley, P., Priebe, S., og Kaiser, W. (1997). Measuring the quality of life of severely mentally ill people using the Lancashire Quality of Life Profile. Social Psychiatry and Psychiatric Epidemiology, 32, 76 – 83.

Phelan, M., Slade, M., Thornicroft, G., Dunn, G., Holloway, F., Wykes, T. et al. (1995). The Camberwell assessment of needs:The validity and reliability of an instrument to assess the needs of people with severe mental illness. British Journal of Psychiatry, 167, 589-595.

Pinikahana, J., Happell, B., Hope, J. and Keks, N. A. (2002). Quality of life in schizophrenia: A review of the literature from 1995 to 2000. International Journal of Mental Health Nursing, 11, 103–111.

Ruggeri, M. Warner, R., Bisoffi, G., Fontecedro, L. (2001). Subjective and objective dimensions of quality of life in psychiatric patients: a factor analytical approach. The South Verona Outcome Project 4. Br J Psychiatry, 178, 268-275.

Saleebey, D. (2011). Some Basic Ideas About the Strenght Perspective. In F. J. Turner (eds), Social Work Treatment. Interlocking Theoretical Approaches (p. 477-485). USA: Oxford University Press.
Salokangas, R. (1994). Community care and need for treatment of schizophrenic patients in Finland. Br J Psychiatry; 164: 115-120.

Sainford, F., Becker, M. and Diamond, R. (1996). Judgement of quality of life of individuals with severe mental disorder:Patient self-report vs provider perspective. American Journal of Psychiatry, 153, 497-502.

Schneider, J., Wooff, D., Carpenter, J., Brandon, T. og McNiven, F. (2002). Community mental healthcare in England:associations between service organisation and quality of life. Health and Social Care in the Community, 10(6), 423-434.
Slade, M.(1994). Needs assessment. Involvment of staff and users will help to meet needs. Br J Psychiatry; 165, 293-296.

Slade, M., Phelan, M., Thornicroft, G., Parkman, S. (1996). The Camberwell Assessment of Need (CAN): Comparison of assessments by staff and patients of the needs of the severely mentally ill. Soc Psychiatry Psychiatr Epidemol, 31, 109-113.

Slade, M., Leese, M., Ruggeri, M., Kuipers, E., Transella, M. og Thornicroft, G. (2004). Does Meeting Needs improve Quality of Life? Psychoterapy and Psychosomatics, 73, 183-189.

Svavarsdóttir, S.J., Ólafsdóttir, K.V., Sturludóttir, E. og Júlíusdóttir, S. (2012). Psychiatric Group Work in Social Skill Training. Social Work With Groups. A Journal of Community and Clinical Practice, 35(2), 103-123.

Svavarsdóttir, S.J., Lindqvist, R. and Júlíusdóttir, S. (2014). Mental Health Services and Quality of Life. The International Journal of Psychosocial Rehabilitation. Vol (18) 2, 72-88.

Sveinbjarnardóttir, E. and Thorlacius, G. (2014). Snúast kosningar til sveitarstjórna um alvörumál? [Are the municipality elections about real matters?] Fréttablaðið,22nd of May,24.

Sveinsson, Ó., Þorleifsson, K., Aspelund, T. and Kolbeinsson, H. (2012). Rannsókn á áhættuþáttum hjarta- og æðasjúkdóma hjá geðklofasjúklingum á geðsviði Landspítala [Research on coronary disease risk factors among schizophrenia patients in the mental ward at the National Hospital]. Læknablaðið (The Icelandic Medical Journal), 98 (7-8), 399-402.

Van Nieuwenhuizen, C., Schene, A., Boevink, W., Wolf, J. (1998). The Lancashire Quality of Life Profile: First experiences in the Netherlands. Community Mental Health Journal, 34(5), 513-524.

Voruganti, L., Heslegrave, R., Awad, A.G. and Seeman, M.V. (1998). Quality of life measurement in schizophrenia:reconciling the quest for subjectivity with the question of reliability. Psychological Medicine, 28, 165-172.

Warner, R., Girolamo, G.D., Belelli, G., Bologna, C., Fioritti, A. and Rosini, G. (1998). The quality of life of people with schizophrenia in Boulder, Colorado and Bologna, Italy. Schizophrenia Bulletin, 24, 559-568.

World Health Organization (1997). Programme on mental health. Measuring quality of life. Retrieved January 10, 2014 from January 2014 from: http://apps.who.int/iris/bitstream/10665/63482/1/WHO_MSA_MNH_PSF_97.4.pdf.