

QUALITY OF LIFE AND UNCERTAINTY IN ILLNESS FOR CHRONIC PATIENTS

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Abstract:

The experience of chronic illness, together with physical impairment and hospitalization in some cases, can be a difficult occurrence to manage. Illness determines changes in patients' life style and limitations, that often cause psychological distress. It may happen that patients neither understand the meaning of the events correlated with illness, nor can predict when such events will occur. This uncertainty augments the negative impact of the state of chronic illness on patients' quality of life.

The present study has the purpose to examine the correlations between uncertainty due to chronic disease and patients' quality of life, keeping into account the diverse coping strategies adopted and the anxiety/depression feelings developed during hospitalization.

There is an inverse correlation between chronic patients' quality of life and the diverse dimensions of uncertainty in illness as identified by the Mishel Uncertainty in Illness Scale. The paper suggests how uncertainty hampers the possibility that patients choose coping strategies, involving their active management of illness. The lower the uncertainty, the higher is the possibility of activate coping mechanisms based on the acceptance of illness, together with a reflexive attitude concerning the actions to be taken to reduce the risk of anxiety/depression during hospitalization.

Finally, the present study presents some policy implications, suggesting how the medical staff should not only treat patients, but also help patients to elaborate problem solving strategies and to positively accept their chronic health state.

Keywords: Uncertainty, quality of life, chronic patients, coping, anxiety/depression.

INTRODUCTION

The experience of chronic illness, together with physical impairment and hospitalization in some cases, can be a difficult occurrence to manage. Illness determines changes in patients' life style and limitations that often cause psychological distress. Moreover, being in hospital provokes a change in interpersonal relationships, habits and daily life; hospitalization entails many unknowns for patients (Dennis, 1987; Gammon, 1998), and may compromise their psychological well being and, therefore, affect their physical recovery and medical compliance.

Uncertainty in illness arises because people neither understand the meaning of events correlated with illness, nor can predict when such events will occur (Mishel, 1997). Uncertainty augments the negative impact of the state of chronic illness on patients' quality of life, *i.e.*, on the subjective perception of the "*key physical, psychological, social and spiritual domains of life*" (the WHO QoL Group, 1998). There is evidence that uncertainty of illness hampers patients' coping strategies, defined as the cognitive and behavioral efforts made "*to master, tolerate, or reduce external and internal demands and conflicts among them*" (Lazarus and Folkman, 1984). Some studies as Hilton (1989), Christman (1990) and Mishel and Sorenson (1991), stressed the existence of a correlation between coping and uncertainty in illness. It emerged how severe symptoms determined by the disease, as high levels of pain, when interacting with uncertainty, may reduce each patient's ability to manage them.

The present study has the purpose to examine the correlations between uncertainty due to disease in chronic patients and their quality of life, keeping into account the diverse coping strategies adopted and the anxiety/depression feelings developed during hospitalization.

The study is organized as follows: the next section describes the tools used to monitor patients' quality of life, as well as uncertainty and coping; results of the correlations among measures of the quality of life, the several dimensions of uncertainty and the different coping strategies are then presented and discussed. Finally, some conclusions, from which it is possible to infer implications for further research, are drawn.

MATERIALS AND METHODS

The present study is observational. It has been carried out in the period January 2014-March 2014 at the Presidio Ospedaliero "Ferrarotto Alessi" in Catania, Italy.

A questionnaire has been administered to a sample of 200 chronic consecutive patients, who accepted to be interviewed at four distinct operative units: Cardiology, Cardiosurgery, Angiology and Vascular Surgery.

The questionnaire was compounded of six sections:

- The first section includes questions related to age, schooling, marital status and some traits related to patients' clinical history, as former hospitalizations, medical visits undergone by the patients during the last year because of the pathology, assessment of health status since the last visit to the moment of the interview.
- The second section contains the *EuroQol-5 Dimensions* (EQ-5D) questionnaire (EuroQoL Group, 1990), frequently used to evaluate health programs. The EQ-5D categorizes patients' health state within five dimensions: Mobility, Self Care, Usual Activities, Pain/Discomfort, Anxiety/Depression. It has been administered together with the *Visual Analogue Score* (VAS), a tool through which patients are asked to indicate on a graduate scale how they feel at the moment of the interview (Drummond et al., 1987).

- The third section concerns the *Short Form Health Survey 36* (SF-36), a tool widely used to assess health related quality of life (Brazier, Harper, *et al.*, 1992; Ware and Sherbourne, 1992), that includes nine dimensions: general health perceptions, changes in health status, physical functioning, physical role functioning, emotional role functioning, social role functioning, bodily pain, vitality, mental health.
- The fourth section includes the *Mishel Uncertainty Illness Scale* (MUIS), that allows to assess patients' perceptions about illness-related uncertainty (Mishel, 1981). The scale is made up of four factors: Ambiguity, Complexity, Inconsistency and Unpredictability. Ambiguity concerns the indistinctness of “[T]he cues about the state of illness that are vague and indistinct and tend to blur and overlap”. Inconsistency refers to the information received “that either changes frequently or is not in accord with information previously received”. Complexity takes into account “[T]he cues about the treatment and the system of care that are multiple, intricate and varied”. Finally, Unpredictability refers to “the lack of contingency between illness and treatment cues and illness outcome” (Mishel, 1997).
- The fifth section is related to the *Coping Orientation to Problems Experienced* (COPE) questionnaire, (Carver *et al.*, 1989; Sica *et al.*, 1997a, 1997b), aimed at analyzing coping strategies adopted by patients to react to the state of illness. The tool consists of five large and independent dimensions: Social Support, Avoidance Strategy, Positive Attitude, Problem Orientation and Transcendent Attitude.
- The sixth and last section of the questionnaire has seen the administration of the *Hospital Anxiety and Depression Scale* (HADS), to detect the level of anxiety and depression for those patients who were hospitalized (Zigmond and Snaith, 1983; Bjelland *et al.*, 2002).

The questionnaire has been administered through face-to-face interviews. The objectives of the research have been clearly explained to patients before proceeding to the interview; in some cases, patients have received further clarifications about those questions who could result more difficult to understand. The average administration time of the questionnaire in all its six parts, was of 20 minutes.

RESULTS

Patients interviewed for the purpose of this study were on average, 65.7 years old; 53% (106 patients) were males and 47% (94 patients) were females. The majority (79% - 158 patients) were married or lived with someone; 15% (30) were widower, and 6% (12) were single.

As far as education was concerned, 60% (120 patients) completed primary school, 35% (70 patients) completed high school and only 5% (10 patients) proceeded to academic and post graduate education.

Table 1. Descriptive statistics.

Demographic variables	Frequency	%
Gender		
Males	106	53 %
Females	94	47 %
Total	200	100 %
Age		
≤ 40	3	1.5 %
41 – 50	11	5.5 %
51 – 60	48	24 %
61 – 70	70	35 %
71 – 80	56	28 %
>80	12	6 %
Total	200	100 %
Marital Status		
Married /living with somebody	158	79 %
Single	12	6 %
Widower	30	15 %
Total	200	100 %
Education Level		
Primary School	120	60 %
Secondary School	70	35 %
Academic Education	9	4 %
Post-graduate Education	1	1 %
Totale	200	100 %

Most of the people interviewed have been experiencing chronic illness for a number of years ranging from 2 to 11. 66 % of patients had been previously hospitalized because of it.

At the time of interview, almost 87% of patients declared that, compared to the previous control visit, their health conditions had improved or remained unchanged.

Table 2. Patients' clinical conditions, frequencies and percentages.

Patients clinical conditions	Frequency	%
Number of years since diagnosis		
< 2 years	43	22%
from 2 to 11 years	128	64%
from 12to 21 years	19	9%
>21 years	10	5%
Total	200	100%
Previous episodes of hospitalization		
Yes	132	66%
No	68	34%
Total	200	100
Numer of visits		
≤ 1	30	15%
from 2 to 6	128	64%
from 7 to 11	17	9%
from 12 to 16	12	6%
from 17 to 21	5	2%
from 22 to 26	7	3%
>26	1	1%
Total	200	100%
Health status comparing to last visit		
Less severe	40	20%
Unchanged	93	47%
More severe	67	33%
Total	200	100%
Information about the disease		
Unchanged	173	87%
Increased	18	9%
Reduced	9	4%
Total	200	100%

Before proceeding to the study of the correlations among the measures of quality of life, uncertainty and coping, it has been necessary to check their internal consistency, by means of the calculation of their Cronbach's Alphas.

As far as the COPE scales were concerned, the internal consistency exhibited an optimal value for the dimension Social Support (Cronbach's $\alpha = 0.88$), good for the dimensions Positive Attitude (Cronbach's $\alpha = 0.74$), Problem Orientation (Cronbach's $\alpha = 0.76$) and Transcendent Attitude (Cronbach's $\alpha = 0.78$), and acceptable for the dimension Avoidance Strategy (Alpha = 0.65). The internal consistency for the HADS scales was good for the dimension Anxiety (Cronbach's $\alpha = 0.81$) and barely acceptable for the dimension Depression (Cronbach's $\alpha = 0.58$). Three of the four MUIS scales exhibited high/satisfactory values of Cronbach's α , namely, Ambiguity (Cronbach's $\alpha = 0.81$), Complexity (Cronbach's $\alpha = 0.79$) and Inconsistency (Cronbach's $\alpha = 0.82$). Only Unpredictability exhibited a poor internal consistency (Cronbach's $\alpha = 0.31$) and, for this reason, it was dropped from the subsequent analysis.

The descriptive statistics relative to the above mentioned scales, together with information concerning the Health Related Quality of life, have been calculated and reported in Table 3.

Table 3. Health Related Quality of Life, Uncertainty and Coping.

Variable	Average	Standard Dev.	Min	Max	Possible Range
VAS 1-100	50.71	21.56	0	100	0 – 100
EuroQol5D	0.64	0.22	-0.056	1	-0.594 – 1
SF 36 General Health	42.47	11.31	10	97	0 – 100
SF36 Changes in Health	3.3	0.88	1	5	1 – 5
SF36 Physical Functioning	59.12	28.48	0	100	0 – 100
SF36 Physical Role Functioning	26.5	42.20	0	100	0 – 100
SF36 Emotional Role	26,16	42.77	0	100	0 – 100
SF36 Social Role	50.37	8.76	12	75	0 – 100
SF36 Pain	42.90	16.97	12	100	0 – 100
SF36 Vitality	38.37	17.09	0	100	0 – 100
SF36 Mental Health	64.46	14	0	100	0 – 100
Ambiguity (MUIS)	41.74	8.92	17	61	13 – 65
Complexity (MUIS)	26.81	5.35	11	35	7 – 35
Inconsistency (MUIS)	16.84	6.52	7	33	7 – 35
Social Support (COPE)	34.97	6.79	16	48	12 – 48
Avoidance Strategy (COPE)	29.04	4.73	18	48	16 – 64
Positive Attitude (COPE)	33.74	3.86	22	48	12 – 48
Problem Orientation (COPE)	29.82	5.39	20	47	12 – 48
Transcendent Attitude (COPE)	28.32	3.25	16	32	8 – 32
Anxiety (HADS)	9.24	3.81	0	20	0 – 21
Depression (HADS)	5.34	2.91	0	14	0 – 21

Both the VAS score and the total SF-36 score have a possible range which goes from 0 to 100. From Table 3 it is possible to notice that the average VAS score (= 50.71) is higher than the total SF-36 (= 42.47). As far as the EQ-5D score, that usually goes from 0 (worst possible health state, *i.e.* death) to 1 (state of full health), it may be noticed that its minimum value reported is negative (= -0.056); this circumstance indicates how some individuals may consider their actual health state as worse than death.

The partial SF-36 score concerning the change in the actual health state, compared to the health state experienced in the previous year, has an average value of 3.3, in a range going from 1 to 5. This suggests that, on average, patients have experienced a worsening in their health conditions.

Considering the scores of the other seven dimensions of the SF-36, it is worthwhile noticing that the higher average scores are those concerning the Physical Role Functioning (26.5), Social Role (50.37), Pain (42.9) and Mental Health (64.46).

Comparing the scores of the five dimensions of COPE, and taking into account the diverse value ranges in which they may fall, it is possible to argue that the most common coping strategies in the sample considered are Social Support and Positive Attitude.

Finally, concerning HADS, for those patients who were hospitalized, Anxiety is the most acutely experienced dimension, comparing to Depression.

The final step of the analysis has been the calculation of the correlation among patients' quality of life measures, the MUIS, the COPE and the HADS dimensions (Tables 4 and 5).

Table 4. Correlations among the diverse measures of patients' quality of life.

	VAS	EQ-5D	SF-36 GH	SF-36 CH	SF-36 PF	SF-36 PRF	SF-36 ER	SF-36 SR	SF-36 P	SF-36 VT	SF-36 MH
VAS	1.00										
EQ-5D	0.55***	1.00									
SF-36 GH	0.46***	0.39***	1.00								
SF-36 CH	-0.43**	- 0.36***	- 0.30***	1.00							
SF-36 PR	0.48***	0.63***	0.32***	- 0.19***	1.00						
SF-36 PRF	0.29***	0.28***	0.21***	- 0.17***	0.37***	1.00					
SF-36 ER	0.28***	0.30***	0.19***	- 0.17***	0.38***	0.82***	1.00				
SF-36 SR	0.06	0.15**	0.03	-0.03	0.14**	0.08**	0.10	1.00			
SF-36 P	0.46***	0.58***	0.37***	- 0.26***	0.52***	0.21***	0.20***	0.26***	1.00		
SF-36 VT	0.378***	0.48***	0.43***	- 0.30***	0.42***	0.39***	0.44***	0.18	0.51***	1.00	
SF-36 MH	0.43***	0.47***	0.39***	- 0.18***	0.35***	0.31***	0.27***	0.14***	0.47***	0.59***	1.00

*** Significance level 99% ($p < 0.01$); ** Significance level 95% ($p < 0.05$); * Significance level 90% ($p < 0.10$).

Table 5: Correlations among VAS, EQoL5D, SF36 and the dimensions of MUIS, COPE and HADS.

	VAS	EQ-SD	SF-36 SG	Ambig	Incons	Comp	Social Sup	Avoid. Strat.	Posit Attit.	Probl. Or	Transc Attit.	Anx.	Dep.
Ambig	-0.3287**	-0.24**	-0.36***	1.00									
Incons	-0.14**	0.134*	-0.22***	0.70**	1.00								
Complex	0.10	0.16**	0.16**	-0.60**	-0.75***	1.00							
Social S.	0.01	-0.02	0.11	0.06	0.07	-0.03	1.00						
Avoid.S trat.	0.10	-0.17**	0.03	0.17**	0.36***	-0.36***	0.13*	1.00					
Pos.Attit.	0.15**	0.22**	0.26***	-0.21**	-0.13*	0.13*	0.28**	0.00	1.00				
Prob. Or.	-0.1097	0.0297	0.10	0.05	-0.18**	0.22**	0.27**	-0.33**	0.31**	1.00			
Trans.Att	-0.14**	-0.12	-0.17**	0.10	-0.09	0.06	0.20**	-0.26**	-0.09	0.16**	1.00		
Anx.	-0.38**	-0.46**	-0.32***	0.35**	0.36***	-0.39**	0.15**	0.21**	-0.18**	-0.02	0.12*	1.00	
Dep.	-0.35**	-0.39**	-0.30***	0.27**	0.18**	-0.17**	0.01	-0.13*	-0.12*	0.26**	0.19**	0.52**	1.00

*** Significance level 99% ($p < 0.01$); ** Significance level 95% ($p < 0.05$); * Significance level 90% ($p < 0.10$).

Results show that the three instruments to measure patients' quality of life, *i.e.*, EQ-5D, VAS and SF-36, are consistent: their pairwise correlations were all positive ($\rho_{EQV} = 0.55$; $\rho_{EQSF} = 0.39$; $\rho_{VSF} = 0.46$) and statistically significant.

The correlations among the SF-36 General Health State (SF-36 GH) score and each of the SF-36 dimensions, concerning Physical Role (SF-36 PHR), Pain (SF-36 P), Vitality (SF-36 VT) and Mental Health (SF-36 MH) are positive and highly significant, indicating that all these dimensions have a major impact on patients' general well being (Table 4).

In Table 5, the MUIS Ambiguity score shows a weak negative correlation with, respectively, the VAS score (significance level 95%) and the SF-36 score (significance level 95%), and a weak negative correlation with the EQ-5D score (significance level 99%). As higher scores of Ambiguity signal a higher indistinctness of the state of illness, this circumstance suggests the existence of a moderate/weak link between Ambiguity and the overall quality of life.

The MUIS Inconsistency score shows a weak negative correlation with, respectively, the VAS (significance level 95%), the SF-36 (significance level 99%), and the EQ-5D (significance level 90%) score.

The MUIS Complexity score shows, as well, a weak positive correlation with the SF-36 General Health State (significance level 95%), and the EQ-5D (significance level 95%). This is in line with the above results concerning the other two dimensions of the MUIS, as a higher score for Complexity is associated to lower difficulties in interpreting the cues about the treatment and the system of care.

About the COPE and its dimensions, the Avoidance coping strategy shows a positive weak and moderate correlation with, respectively, Ambiguity (significance level 95%) and Inconsistency (significance level 99%), whereas it exhibits a negative moderate correlation with Complexity (significance level 99%).

Instead, Problem Orientation, that could be seen as a coping dimension going in the opposite direction of Avoidance, shows a weak positive correlation with Complexity (significance level 99%) and a negative correlation with Inconsistency (significance level 95%).

Moreover, the Avoidance coping strategy is positively and moderately correlated with Anxiety in hospital (significance level 99%) and negatively and weakly correlated with Depression in hospital (significance level 90%). The opposite dimension of Problem Orientation presents a weak positive highly significant correlation with Depression in hospital.

These results suggest that the coping strategies based on problems denial and escapism are associated with higher level of the three considered dimensions of uncertainty in illness. Being improbable that the denial of health problems may cause Anxiety, it might be reasonable to posit that Anxiety leads to reality avoidance and illness refusal, while the correlation between Depression and an avoidance approach may be bidirectional: hence, the more inclined to depression patients are, the more they focus on health problems; focusing on health problems may, in turn, cause depression.

The COPE Positive Attitude has a positive weak correlation with, respectively, Ambiguity (significance level 99%) and Inconsistency (significance level 90%), while it shows a negative weak correlation with Complexity (significance level 90%). Moreover, Positive Attitude shows also a weak negative correlation with both Anxiety in hospital (significance level 95%) and Depression in hospital (significance level 90%) and with their global score (significance level 95%).

This suggests that the lower the Uncertainty in illness, the higher is the possibility of activate coping mechanisms based on the acceptance of illness together with a reflexive attitude concerning the actions to be taken, which, in turn, reduce the risk of Anxiety and Depression during hospitalization.

Finally, results show that Anxiety in hospital is moderately and negatively correlated with the VAS score (significance level 99%), the SF-36 General Health State (significance level 99%), and the EQ-5D (significance level 99%). Anxiety in hospital is moderately and positively correlated with Ambiguity (significance level 99%) and Inconsistency (significance level 99%), and moderately and negatively correlated with Complexity (significance level 99%). From this evidence, it is possible to argue that when the patient health conditions are deteriorated and when his/her understanding of the information related to the treatment is low, Anxiety rises.

CONCLUSIONS

The present study proposes an analysis of the relations among quality of life, uncertainty in illness, coping strategies and anxiety/depression in hospital.

The results offer evidence of an inverse correlation between chronic patients' quality of life and the diverse dimensions of uncertainty in illness as identified by the MUIS: the higher the levels of Ambiguity, Inconsistency and Complexity, the lower is the self-assessed measure of patients' quality of life.

The results concerning the correlations between uncertainty in illness and the coping styles Problem Orientation and Avoidance, entailing, respectively, the choice of being active or avoidant in facing the chronic illness, converge in suggesting that uncertainty hampers the possibility of an active patients' management of illness.

From these results, it stems the need of a global patient care design taking into account the tight interaction among clinicians of different specialties. This would allow to provide not only better clinical integrated treatments but, also, to grant patients clear and consistent pieces of information, therefore reducing the dimension of Inconsistency, that, in turn, leads to a higher uncertainty. Medical staff should not only treat patients but also inform them, transmitting the necessary knowledge and advices on the possible life styles with chronic illness and on the way to face therapies' sides effects, helping them not only to elaborate problem solving strategies but to positively accept their chronic health state too.

The acceptance of the chronic illness could also be attained by making patients understand they are not alone in experiencing this condition. This could be done by promoting psychological support groups, which could be either directly managed by patients or coordinated by psychologist. The shared experience of illness would not only help patients to acquire higher self-confidence but would also reduce the uncertainty of illness, allowing to activate coping mechanisms oriented to both a positive acceptance of illness and a proactive attitude; in this way, the risk of Anxiety and Depression in the case of hospitalization would be reduced too.

The present study can give a substantial contribution in interpreting the ways to implement the objectives of continuity of treatments and the integration between hospital and residential care envisaged in the Italian National Health Plan (*Piano Sanitario Nazionale*, PSN) 2011-2013.

The PSN establishes that the continuity of care has to be achieved by means of the collaboration among diverse professional figures, within and outside the hospital, so that the fragmentation stemming from the development of different hyper-specialized competencies may be integrated in a unitary setting.

Moreover, the PSN stresses the necessity to grant the continuity of the treatment among the different assistance levels and, above all, in the delicate boundary between hospital and residential care; further, it envisages the necessity to design a post-discharge path which must be not only *explained* to the patients but also *embraced* by them.

In this way the implementation of the PSN provisions appears feasible. The results in terms of outcome, especially for chronic patients, would be measured by considering quality of life, reduction in uncertainty and activation of effective coping styles.

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