

SOCIAL PERCEPTION OF CANCER AND ITS IMPACT ON THE LIFE QUALITY OF CANCER PATIENTS FROM ROMANIA

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Abstract: In the case of disease, behaviour is a normative experience governed by cultural rules. Thus, it is not surprising that cross-cultural and historical variations about how diseases have been defined and how people have adapted to them over time can be traced. The main objective of this paper is to highlight existing perceptions about disease among the population with cancer from Romania and the implications that their perceptions about the disease increased their life quality. The main factors on which we focus are: perception of cancer, self-construal and life quality. The results that we expect are: on the one hand, the perception that the disease is incurable, with episodes of relapse, that it is strongly represented on an emotional level and that it lacks coherence for patients, which all lead to poor adjustment to the disease and poor life quality. On the other hand, self-perception of oneself as being independent leads to a decreased quality of life.

Keywords: cancer, self-construal, life quality, perception of disease, culture, cognitive models

Cultural patterns linked to the neoplastic disease

The moment one diagnoses a disease, whichever this may be, the attitude that anyone of us adopts is that of understanding what has happened to us, what that diagnosis written on the paper means. Most of the time, the meanings that we attach to a disease are governed by the meanings and labels given to the cultural environment that we come from. This idea is also supported by the specialised studies which view disease as a cultural construct.

The situation becomes even more problematic, if we talk about the establishing of a diagnosis for a serious chronic disease with a high potential of altering life, and one of these diseases is cancer itself. As Miller (2000) also shows, besides managing his / her internal states altered by such a diagnosis, the patient also confronts social challenges whom s/he must face: maintaining his / her state of normality, adapting to altered social relations, adapting to social roles which modify, managing the social stigmatization of the disease s/he is confronted with and maintaining his / her feeling that things are under control.

It has been proved that the cultural factor affects the reaction that the individual will have, once the physician has established his / her cancer diagnosis, once s/he must comply with the treatment requirements and while s/he adapts to cancer. In the case of the persons with metastasis, final stage, cultural factors will influence patient's and his / her caregiver's emotional and behavioural answers to dying and mourning.

Social perception of cancer as a disease causing one's death determines a distortion of patient's image at the level of collective representation; the patient being condemned to death becomes a marginalised person. Also, at the level of collective representation, cancer is regarded as a transmissible disease as well.

A social construct which contributes to the understanding of the disease and implicitly to one's reaction to the disease is *self-construal*. From this point of view, we can speak about two interpretations, different perceptions of self, *independent self* and *interdependent self*, which are thus seen as factors that affect the attitudinal and normative components of the individual. Understanding oneself in relation to others, either as independent or as interdependent, influences cognitions (attention, cognitive representations, cognitive elaborations), emotions (experimenting and expressing some particular emotions) and motivation (cognitive consequence and affiliation).

Markus and Kitayama (1991) speak about the fact that persons, who view their selves as independent, see themselves as stable and separated from the interpersonal context, value self-promotion, autonomy, assertiveness and uniqueness. On the other hand, persons who view themselves as interdependent see themselves as being flexible and connected to others, connected to the social context, valuing group harmony.

Due to the fact that they are included in social and group relations, people with an interdependent perception of themselves can be rather preoccupied with the interpersonal and social consequences of disease, such as the effects that disease can have on the others or on their

social relations. At the other end, people who view themselves as independent, who see themselves as separated from the social context and the relations they have, may be much more inclined to think of the individual consequences of disease and the way in which disease affects their own behaviour, their state of well-being or self-construal.

On the background of these social cognitions linked to disease, people create their own *perceptions linked to disease*. The perceptions linked to disease are organised cognitive representations or beliefs that patients have regarding their disease. Also, recent research shows that perceptions linked to disease, especially in the case of chronic diseases, are associated with self-control behaviour and behaviour linked to life quality.

Some studies highlight the fact that in the case of those patients who generally have negative perceptions about disease, those perceptions are associated with an increasingly severe disability and also with a very slow recovery, independent of the seriousness of the initial medical condition (Botha-Scheepers S, Riyazi N, Kroon HM, 2006).

Thus, we can notice how all social cognitions work together to give an image about disease and an answer concerning disease, a reason for which we can talk about a diseased person's *life quality*.

While confronting cancer, both patient and family can face difficulties resulting from the difference between the expected level of well-being and the one which s/he experiences in reality. Consequently, paying attention to life quality becomes an important factor in taking decisions, finding supportive care and assessing given answers.

Cultural environment has growing influences on oncologic patient's life quality. Here, we can mention the fact that the patterns of establishing cancer diagnosis and the prescribed treatment, historical factors, as well as the beliefs and cultural values differ from one culture to another. Cancer rate varies from one country to another. In many parts of the world, there are very few resources allocated for early detection of cancer and as a consequence, cancer is discovered in very advanced stages. In the countries and cultures where cancer is inevitably connected to pain and death (especially because in most countries pain management is inadequately managed), the suffering associated with such a diagnosis and its destructive effects on life quality seem to be considerably greater than in an environment where pain can be controlled, tiredness can be prevented and one can hope to be possibly healed.

Research methodology:

Hypotheses:

- The perception of the disease as uncontrollable, with serious consequences and greatly represented on an emotional level led to a poor life quality on all its components.
- The self-perception of oneself as independent has negative influences on life quality during illness.

Participants:

Each subject's testing was done by consensual agreement. The patients were informed about the aim of the research, having been explained the aim of the research, as well as the fact that they were volunteers in the study and had the possibility of withdrawing at any moment, if they considered that their rights were infringed or their integrity compromised or their privacy violated. After each patient had expressed his / her agreement, subject testing followed. Testing was done individually under the form of a structured interview. Questions were part of the used questionnaires, each subject being asked the same questions, in the same order. There was not any time limit for them to answer the questions, the personal answering rhythm of each subject being respected.

A total number of 161 patients participated in this study. The patients were considered eligible, as long as they were diagnosed with cancer, were under treatment and were speakers of the Romanian language. The criteria of the study did not include the disease type, localisation and stage, there being only one remark in this respect - the study does not include the diseased patients who were administered a palliative treatment and were in a final stage without a possibility of healing. Also, the study does not include relapsing patients, patients with significant pains or those who are immobile. The age group of the study patients is 30-70, there not being any wish to make differences from the point of view of this criterion or from the point of view of sex.

Used methods:

The questionnaires used for testing were translated into the English language. The translation was done by a group of three translators. The questionnaires were translated from the English language into the Romanian language, retranslated by a second translator from Romanian into English and then the third translator verified the correspondence between the two translations. The fidelity of each questionnaire was measured by computing the internal consistency coefficients of the items (Alpha Cronbach); I also used factor analysis in

order to check the structure of the factors. The questionnaires used are the following: *The Revised Illness perception questionnaire* (Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D. & Buick, D. (2002), *Scala Singelis* (independence – interdependence), which was conceived by Singelis, T. M., Brown, W. J. (1994), *Quality of Life in Adult Cancer - QLAC*.

Statistical methods:

For data analysis, I used multiple hierarchical regression. I have chosen this method first of all because of the fact that our aim was to show the influence of disease perception and self-perception factors on explaining life quality, i.e. the process itself and not the subjects, not wishing to make an estimate of subjects’ values. On the other hand, it is difficult to isolate a causal relation in the absence of an experimental design, multiple linear regression used with an explanatory purpose being the main way of statistically controlling the influence of other variables on the relation between the ones focused on. For the first hypothesis, multiple regression was used by employing the stepwise method, because in their case no clear theoretical pattern had been found on which we could base our factor choice.

Results:

The perception of the disease as uncontrollable, with serious consequences and greatly represented on an emotional level led to a poor life quality.

We will present the data obtained following the statistical analysis of each dimension of life quality emphasising the influence that the factors of disease perception have.

Table 1
Results obtained following the regression analysis focusing on the influence of disease perception on life quality (N=161)

Predictor	Persistent		Consequences		Personal control		Treatment control		Coherence		Cyclical persistence		Emotional rep.	
	B	rsp	B	rsp	B	rsp	β	rs p	β	rsp	β	rsp	B	rsp
Negative feelings			.14	.12	-.28**	-.26	.20*	.17					.27**	.22
Positive feelings													-.38**	-.38
Cognitive problems			.18*	.17			-.15*	-.14			.14	.13		
Pain											.18*	.15	.34**	.29
Tiredness					-.16*	-.15					.26*	.25		
Sexual function											.18*	.18		

In the data obtained, following the comparison of the models efficiency, one can notice the fact that if the factors of personal control and cyclical persistence are included, the efficiency of the model grows ($R^2= 36$, $\Delta R^2= 0,35\%$), which can also be seen in the analysis of the regression coefficients. As a result, the factors which have the most important contribution to the estimation of tiredness are cyclical persistence ($\beta= .26$) and personal control ($\beta= -.16$).

For *sexual function* as a component of life quality, in the first data obtained, following the regression analysis, one can notice the fact that the only factors with which it correlates significantly is disease coherence ($-.13$, $p< .03$) and cyclical persistence ($.18$, $p< .01$). Consequently, the only factor which significantly contributes to the explanation of sexual function, according to the data obtained, following the analysis of regression coefficients is the cyclical persistence of the disease ($\beta= .18$).

In the case of the life quality component which focuses on the *relation between individual and society* during the disease period, one can notice the fact that most of the disease factors significantly correlate with social avoidance, the only ones, in the case of which one does not record significant results, are the factors of personal control and cyclical persistency. Also, we can also mention the fact that as in the case of the other life quality components, social avoidance also correlates negatively with treatment control ($-.15$, $p< .02$) and disease coherence ($-.22$, $p< .00$). If the other predictors are kept under control, one can notice an increasing dispersion in the case of this criterion ($R^2= 0,67$), as in the case of the explanatory power of the estimative model ($\Delta R^2= 0,27\%$), if the factor of disease coherence is taken into account. The analysis of the regression coefficients implies the fact that the only predictor which has a significant contribution in explaining social avoidance is disease coherence ($\beta=-. 22$).

Financial problems. Thus, in the first results, one can notice the fact that the only factors of disease perception which do not correlate significantly with financial problems are those of disease persistence, personal control and treatment control. Also, one can notice that there is a negative relation ($-.13$, $< .04$) between disease coherence and financial problems. By analysing the data obtained in order to compare models efficiency, one can notice that if the predictor of disease consequence was included, the explanatory power of the model grew $\Delta R^2= 0,83$. Also, if we analyse the data of the regression coefficients, we can notice the fact that the only factors of disease perception which contribute to the explanation of financial problems are disease consequences ($\beta=.29$), disease coherence ($\beta= -.14$) and even if there has not been found any noteworthy connection between financial problems and disease

persistence, following the correlational computation, by controlling the variables, disease persistence was found as a factor which contributes to the explanation of financial problems ($\beta = -.17$).

By analysing the results obtained for *disease benefits*, in the first data, one can observe the fact that there are only three factors of disease perception which significantly correlate with disease benefits: disease consequences (.14, $p < .05$), personal control (.13, $p < .05$) and emotional representation (.15, $p < .05$). Also, one can notice that if the factors of consequences and personal control have been included in the regression equation, the explanatory power of the model grows ($\Delta R^2 = 0,34\%$), and if to this model, the factor of treatment control has been added, the explanatory power has again grown ($\Delta R^2 = 0,13$), a growth which can exclusively be considered as having been the result of the influence exercised by treatment control. In conclusion, following the analysis of the correlation coefficients, the only factors of disease perception which significantly contribute to the explanation of disease benefits are disease consequences ($\beta = .16$), personal control ($\beta = .23$) and treatment control ($\beta = -.18$).

The results obtained for *familial suffering* show the fact that each of the factors of disease perception significantly correlate ($p < .00$) with familial suffering, with the specification that the existing connection between familial suffering and personal control, treatment control and coherence, is a negative one. Also, we can notice the fact that if the factors of disease consequences ($\Delta R^2 = 0,52\%$), personal control ($\Delta R^2 = 0,50$) and coherence ($\Delta R^2 = 0,40$) have been included in the regression equation, the explanatory power of those models grows. Thus, as one can also notice in the analysis of the regression coefficients, the factors of disease perception which have significantly contributed to the explanation of familial suffering are: disease coherence ($\beta = -.26$), personal control ($\beta = -.23$) and consequences ($\beta = .22$).

And for the life quality component which measures the modifications which have appeared at the level of *body image* following the healing treatment for cancer, in the first results, one can observe the fact that all the factors of disease perception significantly correlate with this component at $p < .00$. In this situation as well, there are negative relations between body image and the factors of personal control, treatment control and disease coherence. The factor of disease perception which most significantly contributes to the emphasis of the regression model is disease persistence ($R^2 = 24$, $\Delta R^2 = 24\%$), the next factor which contributes to the growing of the model explanatory power are disease consequences ($R^2 = 28,7$, $\Delta R^2 = 0,47\%$), personal control ($R^2 = 32,1$, $\Delta R^2 = 0,34\%$) and coherence ($R^2 = 34$, $\Delta R^2 = 0,17\%$). By analysing the regression

coefficients, one can also notice that among the factors of disease perception which significantly contribute to the explanation of body image, one can find disease persistence ($\beta = .31$), consequences ($\beta = .20$), personal control ($\beta = -.18$) and coherence ($\beta = -.14$).

The *relapse theme* significantly correlates with each factor of disease perception at a significant threshold of $p < .00$. As in the case of the other life quality components, negative relations have been found between the fear of relapse and the factors of personal control, treatment control and disease coherence. By analysing the regression coefficients, one can notice that the only factors of disease perception which significantly influence the theme of relapse are disease consequences ($\beta = .14$), personal control ($\beta = -.15$) and emotional representation ($\beta = .47$).

The self-perception of oneself as independent has negative influences on life quality during illness.

The factors of sexual appurtenance have been included in this hypothesis, so that a better control over the predictors of self-perception may be maintained, as they do not represent a direct interest as far as the objective of our study is concerned.

By analysing the data obtained following the statistic computation, we can notice the fact that perceiving oneself as independent or interdependent has a decreased influence on estimating life quality, being included in the explanation of only a few components of life quality, their share being a modest one.

Table 2
Results obtained following the regression analysis focusing on the influence of self-construal on life quality (N=161)

Predictor	ΔR^2	Sex		Interdependent		Independent	
		B	rsp	β	rsp	B	rsp
Criterion							
Negative feelings	0,01%	.13	.13				
Positive feelings	14%					-.35**	-.33
Cognitive problems	0,08%						
Pain	0,12%					.18*	.11
Tiredness	0,17%					.12	.11
Sexual function	0,07%						
Social avoidance	0,09%						
Financia	0,03%	.20*	.19				
Benefits	0,74%	.16	.11	.15*	.14	-.27**	-.25
Fam. suffering	0,01%						

Body image	0,1%	.10	.10	.10	.09		
Relapse	0,09%						

By analysing the results obtained, we can say that a higher degree of independence can contribute to the amplification of pain ($\beta=.18$) and of the degree of tiredness ($\beta= .12$) which the diseased person feels following the confrontation with cancer.

The women suffering from cancer are more predisposed to finding benefits while being ill, if they perceive themselves as interdependent ($\beta= .15$) in their relations with others.

Perceiving oneself as interdependent also explains the perceptions they have of their physical aspect ($\beta= .15$). By analysing the data obtained, we can observe the fact that the women who have an interdependent perception of themselves can manifest modifications of their body image following the confrontation with the treatments undergone.

As a last piece of information that we can extract from the data obtained (table 5.2), we can mention that apparently women suffering from cancer can have more intense negative feelings ($\beta= .13$) deriving from the disease and can also express their discontent more manifestly in relation to financial aspects ($\beta=.20$). Also, as I have earlier mentioned, women are more inclined to find benefits in the disease ($\beta= .16$) and are more preoccupied by their body image ($\beta= .10$).

Discussions:

The data obtained show that the share of perceptions linked to the disease which help explain life quality is high, especially on certain dimensions. From among the life quality dimensions most highly influenced by disease perception, we can mention fear of relapse, development of negative feelings, body image, suffering linked to family, disease benefits and financial problems. From among the predictors of disease that have obtained the highest percentages in the explanation of life quality, we can notice that emotional representation has the highest scores, especially for fear of relapse, which is followed by the perception of personal control over the disease, the consequences which the disease can have, cyclical persistence and disease coherence.

As a result, we can notice that the moment the disease is experienced on an emotional level as a state of fear, anger, depression, anxiety, the patient will feel the fear of relapse much more intensely, will have the tendency to develop negative feelings linked to the disease much more easily and the physical pain will be felt much more intensely.

Also, we can observe that following the analysis of the data, the fear of relapse, so frequent among cancer patients, also tends to intensify, if the patient feels that s/he has no control over his / her disease.

The perception of the disease as having serious consequences both on a personal level and on a familial level leads to the perception of a lower life quality in all its dimensions. The highest percentage is that which explains financial problems, those linked to cognitive capacity, body image and familial suffering, but also to fear of relapse.

If the patient does not succeed in finding meaning in his / her disease, in understanding it, in attributing certain causes or significations to it, the disease will lead to a lower life quality, especially because of the patient's tendency of isolating himself / herself, of imagining scenarios connected to the members of his / her family becoming ill as well. Also, one can notice a lower life quality, if the disease is perceived as having cyclical manifestations, a situation which leads to the intensification of physical suffering and thus, to a lower life quality and a less successful adaptation to the disease.

In the data obtained, we can observe that the perception of one's own self contributes to the estimation of life quality to a lesser extent. However, the perception of oneself as independent influences the appearance of positive feelings, in an inverse relation, which leads to the thought that the persons preoccupied with the satisfaction of their own needs and interests will less often have a positive state of mind in relation to the disease, which nevertheless does not mean that the persons dependent on their relations with others are more predisposed to developing these feelings, at least this results from the data which we have obtained. We could see this as the fact that the development of positive feelings is not dependent on the way people perceive themselves.

It seems that a very clear distinction between oneself and others, the exclusion of others from one's personal space and a main focus on oneself bring problems of a physical nature besides relation problems. It is possible that the patients who see themselves as independent may feel the pain and tiredness associated with the disease and treatment more intensely.

A perception of self which is rather interdependent is beneficial to the patient, because the isolation tendency is much more reduced, this being only a beneficial aspect for the person suffering. As a general idea, women with a higher degree of interdependence are much more predisposed to finding benefits in the disease, benefits which are usually associated with a state of well-being, determining an increase in life quality.

Conclusions:

The perception of the disease can be integrated as a factor which rather influences cognitive structures. The perception about the disease is viewed as a cognitive schema, being a social construct. Thus, as a factor which influences the patients' cognition, this perception linked to the disease is noticed to explain almost all components of life in high enough percentages. In explaining fear, the highest degree is represented by the idea that the disease may start again, which is also reasonable taking into account that this cognitive schema includes the components of consequences, personal control, coherence, persistence, emotional representation. As one can observe, the problems connected to sexuality, isolation and emotional experiences have the lowest impact in explaining life quality.

Both the cognitive perceptions connected to the disease and the self-perception of oneself are social constructs, acquired by the individual following the experiences which one undergoes along the course of one's life in a given cultural environment. What is really surprising following the results obtained in this study is the fact that patients suffering from cancer and living in Romania adopt the same type of behaviour regarding the disease with any other person from a different cultural environment suffering from cancer. Also, the transformations of life quality are the same regardless of the cultural environment the patients come from. Consequently, we could conclude that neoplastic diseases have the same representation at the level of collective imagination regardless of the original cultural environment. The cultural differences concerning one's reaction and adaptation to cancer probably surface on other main components of the person's internal structures. Here, we could especially mention the factors of emotional nature, personality structure, coping strategies, religious behaviours, spiritual experiences, etc.

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