

Original Article

Quality of Life and Chronic Pain: Coping Practises and Experiences of Patients with Musculoskeletal Diseases

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Abstract

Background: The investigation between chronic pain and the experiences of patients with musculoskeletal diseases contributes to a better understanding of their quality of life. Particular consideration has been given to the relevance between the levels of musculoskeletal pain and the dynamic social relationships that the active subjects develop in their daily routine.

Aim: To investigate the experience of chronic pain and the quality of life of patients with musculoskeletal diseases. What is examined is whether the quality of life of patients with musculoskeletal diseases is exclusively or primarily affected by chronic pain or any other factors, such as social relationships, everyday life experiences, family environment, emotional ties, as well play a crucial role.

Methods: The research was based on the heuristic propositions of phenomenology and symbolic interaction. Qualitative research methodology was applied; in particular the semi-structured interview technique was selected and twelve participants took part in the survey.

Results: The experience of pain is accommodated into the everyday life and social relationships of the active subjects and largely mediates the interactions of their social environment. The research participants, through their economic, social and cultural characteristics, form their different experiences and their interpretative schemes seeking for the most important physical or extracorporeal factors that modulate their quality of life.

Conclusions: Most of the participants consider that the economic factor affects, however, it does not solely determine, biological, emotional and social characteristics. Besides, the way participants think and act regarding related biological deterioration, limited leisure activities, ability to work, quality of nutrition and environmental changes can potentially highlight some factors that mediate quality of life in chronic diseases, such as musculoskeletal ones. A fundamental feature of all these issues is the (coping) strategies and interpretative patterns of subjects that arise by the experience of chronic pain.

Key words: qualitative research, living experiences, quality of life, musculoskeletal diseases, chronic pain.

Introduction

The quality of life is a complex concept that includes multiple levels, stages and contradicting interpretations. As a concept, it tries to cast light upon the subjective and objective factors that determine the social and personal well-being of an individual (Guyatt, 1997). Health-related quality of life is an important factor that is

differentiated both in experiencing and in managing chronic pain, as an everyday practice of familiarising and interpreting it. The high percentage and the everyday presence of chronic pain in musculoskeletal disorders can strongly influence a person's quality of life. Chronic pain often leads patients to a sudden physical and social decline, or withdrawal, a fact that certainly

reduces the patients' quality of life (Duffield et al, 2017).

Theoretical Background

Chronic pain

The effect of chronic pain in an individual often tends to be more serious than acute pain; the latter is usually transient while the former persists for extended periods. Chronic pain quite often significantly affects sentimental mood, the personality and social relations, causing psychological discontent, stress and severe personal difficulties. People with chronic pain usually experience emotional and physical problems that often result in daily exhaustion and reduced psycho-social function (Ashburn & Staats, 1999; Phillips, 2009).

Chronic pain is not strictly assessed or evaluated according to medical/diagnostic criteria or by "crystal clear" physical or bodily symptoms (Eisenberger, 2012; Eisenberger et al, 2006). The negative social, psychological and emotional aspects that accompany chronic pain lead to substantial alterations regarding the personal world of intimacy and the environment of close interpersonal relationships. These changes, sometimes serious, other times insignificant, affect the degree of the individual's independence, the sense of identity and one's relation to present and future (Korula, 2008).

Quality of life

The quality of life can be determined by subjective, psychological and social factors (McGall, 1980; Andrews, 1974; Ferrans, 1990). Fayers & Machin describe other factors such as physical and emotional functioning, social roles and economic well-being (Fayers & Machin, 2006). The world health organization quality of life (WHOQOL) connects the multidimensional concept of quality of life with personal satisfaction from human communication to cultural interaction. It also associates both physical and psychological dimensions of everyday life, the degree of independence, social relations, and environmental conditions as well as the spiritual, religious and personal beliefs and evaluations (Kuyken, 1995). Thus, quality of life which is related to chronic pain should be considered as a major public health issue, correlated with various and struggling aspects of socio-economic and cultural sphere (Duenas, 2016; Phillips, 2009).

Musculoskeletal diseases: Musculoskeletal diseases involve a wide range of painful disorders of the connective and muscular tissue, affecting bones, joints and the associated tissue of the human body (Blyth & Noguchi, 2017).

Chronic musculoskeletal disorders and chronic pain development, have replaced infectious diseases and have become dominant forms of disease, not only in Western civilizations but as well in other parts of the world (March et al, 2014). Chronic pain affects about 37-41% of the population worldwide. It is a crucial medical and economic issue with serious socio-economic impact and burden on patients, families and healthcare systems (Zale et al, 2013; Parsons & Symmons 2014).

The connection of musculoskeletal disorders to quality of life can be categorised in three terms, relating to physical, psychological and social dimensions. These dimensions can be combined to retain a crucial role on how a patient interprets, understands and copes in everyday reality with chronic pain and discomfort (Tuzun, 2007). Hunfield et al, considers that chronic pain and the consequent negative responses are the result of the interaction between biological, psychological and social factors. Researchers argue that through acquired forms of interpretation and practical management of chronic pain, the quality of life can be affected, with considerable effects on everyday life and associated bodily reactions (Hunfield et al, 2001).

Method

Design: The survey was conducted, by applying qualitative research methodology involving people with chronic pain due to musculoskeletal problems. The purpose was to explore their interpretative schemes and to properly investigate the everyday practices these individuals apply to cope with chronic pain and discomfort and to manage relevant issues such as distrust, uneasiness and body degradation. We also investigate the impact of these painful experiences regarding their social relationships.

Due to the sensitivity of the aforementioned issues, qualitative research was proposed as a suitable mode to understanding the lived experiences of these people, particularly showing empathy, awareness and mutual trust (Iosifidis, 2008: 21-23; Savvakis 2013).

Besides, the qualitative method is suitable regarding the close investigation of the various, often contradictory, subjective experiences of chronic pain. Sensitive methodological techniques, as those applied in this study, can introduce aspects where our knowledge is insufficient or even blur or cannot be approached with more conventional sociological techniques.

Chronic pain and quality of life are strongly coupled with personal experiences as well as social interactions and cultural determinants and cannot be fully separated from inter-subjective evaluations or feelings.

Taking into consideration not only the interpretative patterns of the individual, but also the practices applied in everyday life (i.e. social action), an attempt is made to link the individual, psychological and social aspects of chronic pain and quality of life to empirical sociological research (Lofgren et al., 2016). Thus, the qualitative investigation of health and illness can cast light upon the multiple ways social agents construct, interpret, perform and practice everyday life, a complicated and difficult task full of manoeuvres, techniques, routines and methods applied in order to make life liveable (Savvakis, 2013).

Participants: Research was conducted using and following the method of targeted sampling in order to select the twelve participants the snowball methodological technique. Taking into account the multidimensional context of illness and chronic pain as well as the complexity of the participants' answers, the selection of subjects was based on the medical diagnosis of specific musculoskeletal disorders (e.g., cervical syndrome, back pain, chronic osteoarthritis, fibromyalgia, rheumatoid arthritis, osteoporosis, etc.).

Moreover, researchers strived to ensure heterogeneity and diversity in terms of age, gender, educational level, type of disease, years of diagnosis and total years of pain. This was a methodological choice to elucidate various aspects of the relationship between chronic pain, quality of life and musculoskeletal diseases.

Collection of data: This survey basically applied the semi-structured interview, which enables the researcher to better grasp an acting subject's social reality, in cases other methodological techniques (e.g. closed questionnaires) are difficult to access (Kallas, 2015).

Quality research through interviews focuses mainly on subjective experiences of pain. This qualitative study strives to understand and interpret the multifaceted and complex chronic pain manifestations in both clinical and non-clinical context (Mitchel, MacDonald & Raymond 2009).

In the field of health and illness, semi-structured (focused) personal interviews have been used in research by both physicians and patients. Specifically, interviews encourage subjects to reflect easily and in depth upon their experiences and the practises they employ in their everyday life in order to cope with difficulties and discomfort (Britten, 2006).

Analysis of data: The analysis of the empirical material was based on heuristic concepts of phenomenology and symbolic interaction. On the one hand, phenomenology focuses on the social agents' daily activities and the way they realise and interpret social circumstances. This allows us to understand the multiple and often struggling ways in which acting subjects live in their world and evaluate their overall experiences (e.g. experience chronic pain and impaired quality of life). On the other hand, symbolic interaction contributes to a unique clarification of the social interactions and mediations in a constant flow of social action (Savvakis, 2013; Smith, 1996).

Ethical Issues: Initially, all participants in this research – when approached - were formally and informally informed regarding the scope, aim and character of the study. More specifically, before the interviews were conducted, all twelve participants were again explicitly informed regarding the purpose of the study and what was anticipated. On a voluntary basis, they formally signed a protocol of informed consensus were they declared their agreement to the further evaluation and potential publication of the results of the study. In order to protect their anonymity pseudonyms are being applied. There is no conflict of interests regarding this study, which was solely sponsored by researchers themselves without any source of funding from any private or public Body or Foundation.

Results

Investigating a complex relationship, such as this between chronic pain and the quality of life in people with musculoskeletal diseases, subjective ways of understanding and interpreting, as well as modes of action and coping practices, as

phrased by participants themselves, are at the core of scientific analysis. The investigation of the relationship between chronic pain and quality of life in people with musculoskeletal disorders has taken into account four interrelated criteria: exacerbation of pain; reasons that contribute to its aggravation; factors that transform the participants' quality of life, and finally assessment of this quality of life in the subject's/patient's everyday life.

The quality of life is mainly understood by participants through the manifestations and variations of pain. Especially the period of pain exacerbations is crucial as it amends the whole interpretive schemas and everyday coping practices of these individuals. All participants argue that due to musculoskeletal pain, their quality of life has been greatly affected. This is particularly evident in their everyday life; however the difficulty is increased in the period symptoms become more evident

The combination of physical, psychological and social factors that affect the individuals ultimately contributes to different practises and shapes corresponding patterns of social action that give meaning, illustrate and materialize the concept "quality of life". Subjects' evaluations reinforce the connection between musculoskeletal pain and the quality of life and how this is particularly understood and experienced.

Pain exacerbation

One narrator demonstrates in a characteristic way the impact of pain concerning the evaluation of the quality of her life. As she describes the impact of pain is so great that she has nearly lost her physical functionality. This retains a negative effect not only on her daily routine, but also on key areas such as self-management.

"What do you think? if you are in pain you can't go out, you can't go anywhere you wish, even self management is impaired. The quality of life has changed, hasn't it?"
(Dimitra)

Another participant assesses the role of the family environment during the exacerbation of symptoms. He argues that the quality of life does not solely include personal criteria, albeit is strongly coupled with social circumstances. As he reflects upon a certain period of pain exacerbation, D. mainly seeks support from the family environment. He notably characterizes as

strangers those who are not part of the closer family network and possible supportive or empowering actions from "others" create additional negative emotions.

"No, many things I cannot do. I need help. I'm looking for help in my family environment only. Because I am closer to my family environment, I feel more intimate. Now I do not want strangers, I do not want their pity. I do not want them to help me" (Dimitris)

Aggravating pain

Participants specifically refer to the underlying factors they consider important, forming the subjective perception of quality of life. A narrator mainly mentions the negative factors of her social environment that has shaped most of her daily routines. Negative conditions, mainly through her bad emotional and psychological condition, coupled with poor economic conditions, have disproportionately affected the image of herself, the sense of identity and her place in society.

The acting subject emphasizes on these particular factors that has significantly shaped and influenced the ways she practices her everyday life, her experiences and interpretive patterns that link chronic pain to quality of life. Therefore, she refers to the factors which contribute to pain exacerbation and unique emotional factors.

"I think it is more the psychological factor. Because if someone is always sad, whenever I have no money, to spend which I never had. I had a grandmother who gave me one thousand drachmas a month. If she did not buy me shoes I would not have anything. When I went to school I was still sad, I was always sad. My father would continue to shout every day in the house. He was drunk, throwing things, waving hands and yelling to me. I was afraid when he came in the house, would be really scared. Growing with anger and fear, these things certainly affected me"?
(Vasiliki)

Another participant notably articulates her poor and frustrated financial situation. She refers to this social characteristic as a determining factor that contributes not only to the formation of pain but generating the manifestation of her autoimmune disease as well. The economic crisis acts catalytically on the psychological state of the narrator and tends to influence both the action and interpretation of the acting subject.

The poor economic situation, coupled with the daily demands, produce a really frustrating and hard reality. Increased obligations had given raise to an unbearable burden while reshaping the quality of life in more negative turns. M. categorizes the economic crisis as a structural feature that characterizes many of the properties and responses of today's society. This becomes apparent when better economic conditions in the past formed a quite different image of the subject, with a different sense of self, different margins of social action and self thinking and increased spaces for social action.

"I got the autoimmune disease due to the economic crisis. I had lost my world, how could I manage it? I was losing my home, I lost everything. For me the main factor was the economic one this why I experienced autoimmune disease. It affects your psychology, all around you are collapsing. How do I get it over, when my psychology goes down? You see everything black and it is rational. Whether we like or not, we live a life in which everything is black and toxic. When I look back into the past I can only remember being financially well. I had no economic worries and I was happy. When the crisis came along I was under so much stress" (Marianthe)

According to the above mentioned, the economic factors seem to characterize and shape the perceptions, attitudes and different forms of actions that each subject adopts. Through circumstances that have been reshaped – as effects of the economic and social crisis in Greece – all the spectrum of social action seems to have been affected. Narratives are characterized by their apparent link to the economic factor that can affect biological, emotional and social characteristics.

Through the impact of this ongoing crisis, the economic factor is assessed as the most important one, as it has reshaped the quality of life, mainly through negative consequences. Money is assessed as an essential means of living; serving as an important condition that determines social reality, re-shaping social identity. Furthermore, the monetary based economy and the difficulty of taking part in it, functions as a key factor on the one hand on the self-esteem level of health of the subjects, on the other hand, on social relationships. Due to the economic factor, there are differences in health

between different socio-economic groups of the population. In addition, through the creation of poor social groups, health and illness issues exist as well a considerable lack of goods and abilities that prevent the individual from living a dignified and independent life, thus redefining the concept of quality of life.

Besides the above aforementioned, a narrator considers that the environmental issues are important factors in that they can contribute to changes in the human body. She argues that both dramatic and environmental changes are a result of human intervention in nature and the consumption of chemical substances in the food chain reshape the older, better conditions. These transformations install and manifest various aggravating and problematic situations in the human body. Consequently, nutrition plus the environment are the factors that mediate the quality of life, which has been negatively affected.

"It is certainly the environment; everything we eat affects us, negatively. There is nothing pure anymore. Everything is now killed with drugs; the atmosphere is no longer the same as it was in the past. Now everything is contaminated, you do not see what's going on around us, life has been very difficult. My children told me today that yesterday the temperature was 30 degrees Celsius and within one hour it went down to 6. A phenomenon which had never happened before. All this changes severely affect the human body. The weather affects me a lot. Whenever the weather changes, the pain and dizziness along with bad mood and psychological decline begin" (Georgia)

Quality of life

Another important feature that is strongly connected to the quality of life is the time frame along with the evolutionary processes of the disease. A participant considers that due to the limitations caused by the pain in his physical functioning, his quality of life has dramatically changed.

His everyday habits, as well as leisure activities, are determined by the insecurity that causes the feeling of distrust, uneasiness and fear. Fear replaces pain greatly as the subject adjusts his needs and abilities, considering the risk of an endangered pain and recurrence of pain.

“There is no degree and way. There is only 50% of my life left. I'm afraid not to make any wrong moves to worsen condition and injure myself worse. As I stated before, I cannot enjoy nature. In order to enjoy nature you have to climb a mountain, descend some rocks. How can you do that just walking on the cement and asphalt, you do not enjoy nature” (Christoforos)

A narrator explains the problematic situation that prevails in his everyday life. It clearly argues that his quality of life has considerably changed, notably through restrictions on issues of self-sufficiency and self-management. He claims a change in his regularity and the transformation of its everyday life through the limitations of disease in areas such as nutrition, entertainment, education.

In addition, fundamental social relationships are affected, as illness creates a barrier between him and the people who wish to be closer to him. This creates a problematic situation that affects deeper aspects in his identity and role of the subject as it shapes his perceptions and attitudes about his choices and his ways of acting.

“Yes, entirely. First of all the food, I cannot eat whatever I want. As far as entertainment is concerned the same applies. Spiritual food; I cannot read whatever I want, I cannot see a film I want, I cannot go wherever I want, I cannot live with the people I want. There is always the pain issue. At least I could in the past imagine freedom. Now I cannot even imagine it” (Hiraklis)

Conclusion

As narrators point out, the quality of life, which is evaluated and analyzed, is strongly related to the experience of chronic pain in everyday life. This is the key component that considerably shapes the attributes connected to physical, emotional, cognitive and social characteristics of a patient. The quality of life is associated with health, physical, emotional and social properties as well as the prevailing socio-economic and cultural conditions. In general, quality of life is formulated in terms of features and properties that (2006) promote physical functioning, emotional uplifting and daily autonomy.

The quality of life is inextricably linked to the evolutionary course of illness and the consequent impact of pain on the daily routine. Narrators assess their quality of life by considering a

comparative perspective based on physical functions and social actions that existed prior to their illness. The way in which the quality of life is assessed is in accordance with the individual's experience as well as with the interactions of his social environment.

An important finding is that the majority of subjects believe that the economic factor can affect biological, emotional and social characteristics. In addition, the subjects' assertion on the issues of biological deterioration due to aging, limited leisure activities, working ability, the quality of nutrition, environmental changes can highlight a number of factors that link quality of life to chronic pain.

Another finding is that social actions and interpretive schemes that arise from the experience of chronic pain, especially fear and anxiety result in a restricted and limited version of the self and her/his abilities. The fear of constant pain greatly reduces and determines the quality of life affecting their activities and reshaping everyday interactions.

Discussion

The quality of life is inextricably linked to emotions which accompany the evolutionary course of the illness as well as the daily interactions with social environment. The quality of life is conceived through interpretations connected to social parameters and cultural data. For this reason, the quality of life is connected to chronic pain and evaluated on the basis of physical, psychological and social processes that are present in the everyday life of the participants and their experiences due to musculoskeletal disorders.

References

- Andrews, F., (1974). Social indicators of perceived life quality. *Social indicators research*, 1(3), 279-299.
- Ashburn, M. & Staats, P., (1999). Management of chronic pain. *The Lancet*, 353(9167), 1865-1869.
- Blyth, F. & Noguchi, N., (2017). Chronic musculoskeletal pain and its impact on older people. *Best practice & research clinical rheumatology*, 31(2), 160-168.
- Britten, N., (2006). Qualitative interviews. In: C. Pope & N. Mays, eds. *Qualitative research in health care*. London: Blackwell publishing.
- Duenas, M., Ojeda, B., Salazar, A., Mico, J. A., & Failde, I., (2016). A review of chronic pain impact on patients, their social environment and

- the health care system. *Journal of pain research*, 9, 457-467.
- Duffield, S., Ellis, B., Goodson, N., Walker-Bone, K., Conaghan, P., Margham, T., & Loftis, T., (2017). The contribution of musculoskeletal disorders in multimorbidity: Implications for practice and policy. *Best practice & research clinical rheumatology*, 31(2), 129-144.
- Eisenberger, N., (2012). The neural bases of social pain: Evidence for shared representations with physical pain. *Psychosomatic medicine*, 74(2), 126-135.
- Eisenberger, N. I., Jarcho, J. M., Lieberman, M. D. & Naliboff, B. D., (2006). An experimental study of shared sensitivity to physical pain and social rejection. *Pain*, 126(1-3), 132-138.
- Fayers, P. & David, M., (2006). *Quality of life, evaluation, analysis and interpretation*. Thessaloniki: University Studio Press.
- Ferrans, E. C. (1990). Quality of Life: Conceptual issues. *Seminars in oncology nursing*, 6(4), 248-254.
- Guyatt, H. G. (1997). Measuring health-related quality of life: General issues. *Canadian respiratory journal*, 4(3), 123-130.
- Hunfield, J., Perquin C.W., Duivenvoorden H.J., Hazebroek-Kampschreur A.A., Passchier J., van Suijlekom-Smit L.W., van der Wouden J.C., (2001). Chronic pain and its impact on quality life in adolescents and their families. *Journal of pediatric psychology*, 26(3), 145-153.
- Iosofidis, Th., (2008). *Qualitative methods of research in social sciences*, Athina: Kritiki.
- Kallas G., (2015). *Theory, methodology and research infrastructures in social sciences*, Athina: Kritiki.
- Korula, M., (2008). Psychosocial aspects of pain management. *Indian journal of anaesthesia*, 52(6), 777-787.
- Kuyken, W., (1995). The world health organization quality of life assesment (WHOQOL): Position paper from the world health organization. *Social science & medicine*, 41(10), 1403-1409.
- Lofgren, M., Schuldt - Ekholm, K., Schult, M.- L. & Ekholm, J., (2016). Qualitative evidence in pain. In: K. Olson, R. Young & I. Schultz, eds. *Handbooks in health, work and disability*. New York: Springer.
- March, L. Smith EU, Hoy DG, Cross MJ, Sanchez-Riera L, Blyth F, Buchbinder R, Vos T, Woolf AD. (2014). Burden of disability due to musculoskeletal (MSK) disorders. *Best practice & research clinical rheumatology*, 3(28), 353-366.
- McGall, S., (1980). What is quality of life? *Philosophica*, 25(1), 5-14. Available from: Mitchel, L. & MacDonald, R., Raymond AR, (2009). Qualitative research on pain. *Current opinion in supportive and palliative care*, 3(2), 131-135.
- Parsons, S. & Deborah P.M. Symmons., (2014). The burden of musculoskeletal conditions. *Medicine*, 42(4), 190-192.
- Phillips, C., (2009). The cost and burden of chronic pain. *Reviews in pain*, 3(1), 2-5.
- Smith, A. J., (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & health*, 11(2), 261-271.
- Tuzun, E. H., (2007). Quality of life in chronic musculoskeletal pain. *Best practice & research clinical rheumatology*, 21(3), 567-579.
- Savvakis, M., (2013). *Microsociology and qualitative research. Theoretical examples and empirical applications*. Athina: Kritiki.
- Zale, E., Lange, K., Fields, S. & Ditre, J., (2013). The relation between pain-related fear and disability: a meta-analysis. *The journal of pain*, 14(10), 1019-1030.