

SENSE OF MASTERY IN THE CONTEXT OF COMPLEMENTARY THERAPIES IN MULTIPLE MYELOMA TREATMENT

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BACKGROUND

Conventional medicine represents highly professional methods of treatment which might affect patients' perception of active participation and decision-making possibilities regarding their health. Perceived control was found to be an important psychosocial factor which helps people with chronic disease adjust and cope with their diagnosis (Taylor, Lichtman & Wood, 1984; Neipp, López-Roig & Pastor, 2007). It appears that the use of complementary and alternative medicine serves as a strategy through which people seek to regain control over their health situation (Baarts & Pedersen, 2009). In multiple myeloma diagnosis and treatment, patients' feelings of lack of control may arise and lead to reduced sense of mastery.

Feelings of perceived control and its elements have been researched in relation to many specific types of cancer, as well as to oncology diseases in general. Cancer is considered to be a diagnosis difficult to knowingly prevent or regulate by individual behaviour. In regards to feelings of control, it might be difficult for patients to have a clear idea of how to regulate or control their behaviour or specific actions in order to help their case. On the other hand, in diseases such as diabetes, there are relatively clear instructions of how patients can by themselves actively mitigate the disease, prevent worsening of symptoms or generally improve their health outcomes. In that case, patients recognize specific means of achieving their goal, that is relatively good control over their health outcomes. However, in multiple myeloma, the way to improve patients' results is not as clear. It might seem that there is little one can do, besides the conventional ways of treatment, in order to improve their case. There are multiple ways to improve one's diet, exercise or avoid recognized carcinogens, though without the certainty of any positive impact. The trajectory and prognosis of multiple myeloma is in many cases seemingly unpredictable. In general, there are no specific ways one can prevent cancer or its metastasis throughout one's body. Patients' narratives emphasize the „uncontrollability“ of cancer and its outcomes and the „little they can do in order to help“.

We have chosen mastery as an example of one of many commonly used constructs studied in relation to perceived control. Ellen Skinner (1996) places mastery in the group of constructs related to individuals' motivation for control. Pearlin and Schooler, who designed *The Mastery Scale* (1978) for measuring mastery, define it as „the extent to which one regards one's life chances as being under one's own control in contrast to being fatalistically ruled“ (1978: 5). In the domain of physiological health, Brady adds that „it is conceived as a personality characteristic that serves as a psychological resource individuals use to help them withstand stressors in their environment“ (2003: 155). In their work, Pearlin and his colleagues describe how stressful life experiences or chronic life strains during lifespan may distort one's self-perception and individual feelings of mastery (Avison, Aneshensel, Schieman & Wheaton, 2010).

In our research, we have worked with patients diagnosed with multiple myeloma, a potentially chronic oncology disease. Perceived control is an important psychological construct, however it does not stand on its own, meaning, it does not act in isolation (Wallston, Wallston, Smith & Dobbins, 1987). There are other psychological constructs in interaction, as well as individual social and cultural contexts of patients, their health experiences and values. Additionally, perceptions of control may also „vary depending upon whether outcomes are already known or not“ (Wallston, Wallston, Smith & Dobbins, 1987: 16). A health „outcome“, such as multiple myeloma diagnosis, may therefore influence individual feelings of mastery of oncology patients. Based on these theoretical findings, we decided to measure the sense of mastery of patients with multiple myeloma.

METHOD

The study comprised of both, qualitative and quantitative methodological techniques, namely in-depth interviews, participant observation and questionnaire. We used the Perlin Mastery Scale questionnaire to investigate individual measures of sense of mastery among multiple myeloma patients. Additionally, we conducted 14 in-depth semi-structured interviews about patients' beliefs regarding their disease and its treatment, as well as experiences with biomedical specialists and alternative and complementary medicine.

We conducted the individual interviews in a 3 month period during a field research spent in a hospital department treating multiple myeloma patients. The interviews addressed the following sets of themes: early signs and symptoms; individual experiences with the beginnings of the diagnosis, its trajectory and used types of treatments (biomedical, alternative and complementary); disease and treatment affects on everyday lives; patients' personal beliefs about their disease, its cause and its appropriate treatment; individual perceptions of medical specialists involved in the treatment; available information about biomedical treatments as well as alternative and complementary methods, their individual efforts and efforts of their families to seek information and consultations about treatment; socio-demographic factors and related personal and social contexts of individual patients.

OBJECTIVES

- Identify measures of sense of mastery of multiple myeloma patients
- Explore the way multiple myeloma patients perceive and understand alternative and complementary therapy possibilities
- Explore the relationship between measures of mastery and patients' alternative and complementary therapeutic choices
- Emphasize and demonstrate the benefits of combined quantitative and qualitative methodology in order to provide better individual care

RESULTS

We focused on a relationship between measures of mastery and CAM use of patients with multiple myeloma diagnosis. The average age of participants (n=31) was 63,26 years and the average time since the initial diagnosis was 6,61 years. Patients' average sense of mastery score was 18,53 (SD=1,63) where scores below 20 indicate reduced sense of mastery. In qualitative analysis, we compare individual results with interviews. Based on interview results, we believe many patients use some kind of complementary therapies as an implicit way of maintaining perceptions of control. At the same time, we observed that using complementary therapies and activities reduces feelings of helplessness and stress, therefore positively contributes to the healing process.

As we have already mentioned, Pearlin and his colleagues describe how stressful life experiences or chronic life strains during lifespan may distort one's self-perception and individual feelings of mastery (Avison, Aneshensel, Schieman & Wheaton, 2010). More importantly, it is necessary to note that feelings of perceived control are not considered stable in time. Especially in health related behaviour, they represent a dynamic process evolving with patients' experiences as well as their social and cultural environment. To analyse what exactly shapes low or high measures of perceived control in a specific period of patient's life, treatment or CAM therapy, in-depth interviews are essential to further explain questionnaire results.

That being said, our study shows how feelings of perceived control may change based on specific situations of individual patients and what factors contribute to their consequent choices of CAM treatments. Not only is it important to know the levels of perceived control, but it is crucial to understand what kind of control patients seek and how in order to better understand patients' choices of CAM treatments and possibly help them choose based on their beliefs and individual needs.

One of the objectives of this work is to emphasize that a suitable methodology is crucial in order to better explain feelings of perceived control and individual decision-making regarding CAM. Although *The Mastery Scale* is not designed to measure what kind of control patients seek, it is interesting to examine how specific differences in health beliefs and behaviour can clarify contrasting choices of patients with similar scores of mastery. It is often very difficult to get clear conclusions about patients' health beliefs using questionnaires. Especially in the area of health behaviour, narratives are often essential to grasp the personal contexts of individual circumstances. We present some of the specific examples that we believe demonstrate the benefits of combined quantitative and qualitative methodology.

Complementary & Alternative Medicine

Disease & Treatment Path

Explanatory framework

Doctor

Family & Friends

Perceived control

In socio-scientific research, it is common to regard an oncology diagnosis as a variable correlated with multiple social factors. Certainly, cancer and/or its various types is a unifying element in various social phenomena. However, we believe that the diagnosis of multiple myeloma in some cases cannot be considered a shared variable among the group of patients, since the diversity of its symptoms and complications make it a rather individually distinctive experience.

Multiple myeloma is a potentially chronic disease with many different characteristic symptoms and implications for everyday lives of myeloma patients. Unlike other types of cancer, it does not usually manifest in visible lumps or tumours. Instead, it attacks plasma cells inside patients' bone marrow. Today, there are multiple types of available treatments of myeloma, although some are less accessible in Slovakia. Regardless of their accessibility, every case is unique and therefore requires different type of treatment suitable for each patient. Every patient responds to treatments differently and in some cases, specific treatments do not work at all for some individuals.

Besides treatment, symptoms are another element that is widely diverse. On one hand, there are cases with severe spine and bone damage, kidney failure or mobility problems and on the other, there are patients surviving 15 to 20 years without severe complications. Some patients respond positively to the first course of treatment they try and others try multiple treatments none of which result in success. Certainly, there are many shared physical and emotional issues, however, the diverse symptoms and complications result in very distinct individual experiences with treatment and everyday life.

In the domain of perceived control, the uniqueness of this diagnosis and its characteristics is especially relevant. Specifically, the feelings of mastery patients have might be closely related to the character and intensity of their individual experiences of lack of control. In other words, a patient diagnosed for 15 years without any serious symptoms might have different feelings of control than a patient of 2 years with multiple unsuccessful treatments and severe complications. Furthermore, in relation to CAM, their choices and behaviour are therefore affected not only by their shared diagnosis (which is evident when using quantitative measures), but also by their contrasting experiences with the disease (which is not evident when using a questionnaire).

We compared individual narratives of patients with low measures of mastery. In our particular case, individual beliefs about the disease and its origin (referred to in medical anthropology as *explanatory frameworks*) indicate what type of control patients seek and how. While comparing multiple patients with measures indicating low sense of mastery, we encountered many differences in their CAM use. Patients searched for, what we might call, different kind of control and of course in a different way. Individual beliefs about the diagnosis and its meaning may explain not only what kind of consultations (both CAM and biomedical) patients seek, but also when throughout their treatment trajectory. Feelings of perceived control are not considered stable in time. As the disease evolves and the scope of treatment and its results change, patients' feelings of control tend to change as well. To analyse what exactly shapes low or high measures of perceived control in a specific period of patient's life, treatment or CAM therapy, in-depth interviews are essential to further explain questionnaire results.

The fundamentals of modern biomedicine's legitimacy stand to a large extent on the characteristics of professional science and the expertise of people who represent it. Some patients may feel lack of personal mastery, however, they rely on the doctor to „be in control“. In these cases, patients often do not feel the need to seek alternative treatment or consultations, since they believe they are „in the good hands of the specialists“. A doctor represents a competent authority, an expert and representative of the biomedical treatment. They are also a legitimate source of information about the possibilities of CAM. Trust, confidence or faith in the doctor, however patients describe it, is a very powerful factor in patients' decisions about the use of CAM. Faith in the doctor often means faith in their treatment. Patients themselves often point to the doctor as a reason why „they do not need to seek alternatives, because the doctor has everything under control“.

Analysing personal narratives helps to identify key individuals in patients' surroundings that may help with their efforts to gain control. Even though the results of CAM users show low measures of mastery, it is not enough for us to make specific conclusions about their choices to use CAM. For example, we encountered a patient with a mastery level 15, which can be interpreted as low. The patient has been trying and using multiple types of CAM (energy healer, specific dietary habits and supplements, meditations etc.). From his questionnaire results, we could conclude his low measures of mastery are linked with his extensive use of CAM. However, his narratives tell us otherwise. Although the mastery measures are low and he uses multiple CAM methods, he does not act based on his personal beliefs. Qualitative data analysis demonstrates that the decision to use CAM and continuing with these treatments is his family's choice. His approach to CAM is very passive, he tries what family suggests and continues with what family approves. However, in his own words „he would not do CAM and any of this stuff if his family did not urge him to do so.“ He explains, it is not his desire to pursue consultations and CAM possibilities and he does not care about it as much as his family. In-depth interviews demonstrate that using CAM or additional treatment options does not necessarily mean the patient is looking for more control. Patients might often use CAM based on family's decisions even though they might not feel the need to look for and use other options. Passive patients sometimes use dietary supplements, complementary therapies or activities at the request of their family and friends. That however, is not a demonstration of their personal beliefs and expectations of CAM. This kind of personal context of decision making is often not clear from questionnaire findings which might influence data analysis and results.

CONCLUSION

The aim of this study was to identify measures of mastery of patients with multiple myeloma and explore the relationship between measures of mastery and patients' CAM therapeutic choices. The sample shows reduced overall measures of mastery. However, in some cases, we examined specific inconsistencies between qualitative and quantitative findings which lead us to highlight the necessity of combined methodology for consistent results, especially with rather abstract constructs such as perceived control. It is often very difficult to get clear conclusions about patients' health beliefs using questionnaires. In-depth interview findings repeatedly show more precise, or in some cases even different results regarding patients' perceptions and everyday behaviours. Narratives of how and where patients seek control tell us more about their perceptions than mastery measurements alone. Especially in the area of health behaviour, narratives are often essential to grasp the personal contexts of individual circumstances. In depth interviews reveal specific beliefs and values which affect patients' feelings of control and consequent CAM choices. All of these specific dissimilarities mentioned above contribute to patients' choice of CAM treatment, its nature and what they expect from CAM as a result. Using qualitative methods benefits the research findings in the sense that it sets the quantitative results in relevant psychosocial, historical and cultural context of individuals. Consistent findings about perceived control tell us what kind of control patients seek, when and if they use CAM to do so. That way, for example, interventions can be targeted on specific means to achieve individual results based on patient's needs, instead of his family's. Likewise, in the case of patients relying on specialists to be in control, doctor's involvement and guidance in regards to CAM might be necessary in order to navigate patients process and efforts. However, when it comes to work management and organization conditions, biomedical specialists are not able to fill this role completely. In Slovakia in general, there is an ongoing need for the development of a better integrative care for patients with oncology diagnosis. So far, the Slovak health care system is not adapted to provide satisfactory integrative care. On a systematic level, it is crucial to create an environment for satisfying integrative care provision. However, until this improvement is possible, it is necessary to create a way to help patients with their efforts and decision making regarding their CAM possibilities. Therefore, involving a psychosocial care professional might be very beneficial in order to provide better individual care and help with specific CAM needs of multiple myeloma patients.

REFERENCES:

- Avison, W.R., Aneshensel, C.S., Schieman, S. & Wheaton, B., eds. (2010). *Advances in the Conceptualization of the Stress Process: Essays in Honor of Leonard I. Pearlin*, New York, NY.
- Baarts, Ch. & Pedersen, I.K. (2009). Derivative benefits: exploring the body through complementary and alternative medicine. *Sociology of Health & Illness*, 31(5), 719–733.
- Brady, T. J. (2003). Measures of Self-Efficacy, Helplessness, Mastery, and Control. *Arthritis & Rheumatism (Arthritis Care & Research)*, 49(5S), 147–164.
- Neipp, M. C. López-Roig, S. & Pastor, M. A. (2007). Control beliefs in cancer: A literature review. *Anuario de Psicología*, 38 (3), 333–355.
- Pearlin, L.I. & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2–21.
- Skinner, E. A. (1996). A Guide to Constructs of Control. *Journal of Personality and Social Psychology*, 71(3), 549–570.
- Taylor, S. E., Lichtman, R.R. & Wood, J. V. (1984) Attributions, Beliefs About Control, and Adjustment to Breast Cancer. *Journal of Personality and Social Psychology*, 46 (3), 489–502.
- Wallston, K. A., Wallston, B. S., Smith, S. & Dobbins, C. (1987). Perceived control and health. *Current Psychological Research and Reviews*, 6, 5–25.

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