

The Paradox of Waiting for Heart Transplant: Between Control and Fate

Katarzyna Nowicka-Sauer,^{1,2} Krzysztof Jarmoszewicz,² Małgorzata Pietrzykowska,¹
Sebastian Batkiewicz²

Abstract

Objectives: Understanding a patient's perspective has received increased attention. Awaiting heart transplant remains a great challenge, not only for patients and their families but also for health professionals. This particular challenge has multiple aspects, the most important being the psychological one. Understanding candidates for heart transplant is vital for all caregivers. In this study, our aim was to present the individual's experience of awaiting heart transplant.

Materials and Methods: Structured interviews and the Pictorial Representation of Illness and Self Measure, Hospital Anxiety and Depression Scale, the Illness Cognition Questionnaire, and the Illness Perception Questionnaire-Revised measurements were performed in 2 male patients (60 and 61 years old) who were on heart transplant wait list.

Results: The patients expressed their concerns and perceived severe consequences of heart disease. They also demonstrated the importance of significant others and hope. The results suggest the existence of realistic cognitive pictures of the disease. The patients revealed high sense of control along with the awareness of being dependent on fate. The lack of severe anxiety and depressive symptoms along with high perceived benefits' scores suggest the existence of an adaptation process.

Conclusions: Awaiting heart transplant appears to be a multidimensional phenomenon. The paradoxical configuration of a high sense of control along with the awareness of being dependent on fate was apparent. Significant others and hope seem to be of great importance. The Pictorial Representation of Illness and

Self Measure allows a better understanding of a patient's perspective and allows the patient to share personal views. The individual approach provides opportunities that go far beyond routine clinical assessment.

Key words: *Illness perception, Pictorial Representation of Illness and Self Measure, PRISM*

Introduction

In recent years, attention has been turned toward the patient's perspective of living with chronic disease. This has allowed increased emphasis on patient needs, expectations, and patient-reported outcomes.¹⁻³ The exploration of aspects beyond clinical factors is of a great importance,¹ as knowing patients' perspectives allows the caregiver to understand better the effects of chronic illnesses on patients' lives.^{4,5} The pretransplant period constitutes one of the most challenging life situations, generating extreme stress.^{4,5} Apart from physical suffering, the psychological consequences of waiting for transplant are undoubtedly vital.^{4,6,7} This unique experience seems to be worth a deeper exploration, which may lead to improved care.

Materials and Methods

We present the personal experiences of 2 men (age 60 and 61 years) who were waiting for heart transplant. Clinical and sociodemographic data of the participants are presented in Table 1.

During psychological consultation, the Pictorial Representation of Illness and Self Measure (PRISM) (prisimum GmbH, Zürich, Switzerland) was used to explore the patients' perceptions of illness burden. This measure consists of a white A-4 size board with a yellow circle 7 cm in diameter fixed in the bottom right corner representing the "self." The patient is handed a red disc 5 cm in diameter representing the

From the ¹Department of Family Medicine, Medical University of Gdańsk, and the ²Cardiac Surgery Department, Cardiovascular Centre of Gdańsk, Gdańsk, Poland

Acknowledgements: The authors declare that they have no conflicts of interest to disclose. We would like to thank our patients for participation in the study. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Corresponding author: Katarzyna Nowicka-Sauer, Department of Family Medicine, 2 Debinki Street, 80-211 Gdańsk, Poland

Phone: +48 58 349 1575 **E-mail:** kpsauer@gumed.edu.pl

Experimental and Clinical Transplantation (2017) 6: 696-699

Table 1. Clinical and Sociodemographic Characteristics of Participating Patients

	Patient 1	Patient 2
Age, y	61	60
Education	Occupational	Occupational
Family status	Married, 2 children	Married, 4 children
Employment status	Disability pension	Disability pension
Medical history	Chronic heart failure, left ventricular ejection fraction 8% Left bundle branch block Paroxysmal atrial fibrillation Sustained ventricular tachycardia	Dilated cardiomyopathy Chronic heart failure, ejection fraction 8% Coronary artery disease Diabetes mellitus type 2
Previous medical history:	Coronary artery bypass grafting 1994 Percutaneous coronary intervention 2011 Implantation of implantable cardioverter defibrillator 2012 Three myocardial infarctions in anamnesis Episode of aphasia motorica caused by brain circulation insufficiency 2011	Myocardial infarction 1994 Coronary artery bypass grafting 1995 Percutaneous coronary intervention 2011 Implantation of implantable cardioverter defibrillator 2011

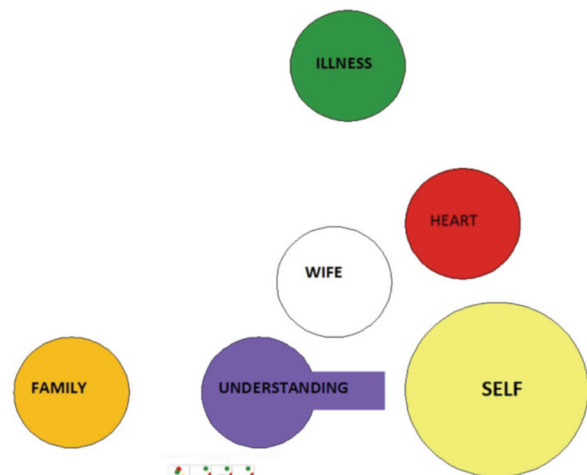
illness and is asked to place it on the board with the following instruction: "Please imagine that this board is your life at the moment. Where would you place this disc to show me how important the illness is in your life right now?" In the present study, we used the PRISM+ version.⁸ To assess the emotional state and illness perception, we used the Hospital Anxiety and Depression Scale (HADS),⁹ the Illness Cognition Questionnaire,^{5,10} and the Illness Perception Questionnaire-Revised (IPQ-R).¹¹ The study protocol conforms to the ethical guidelines of the 1975 Helsinki Declaration and was approved by the university ethics committee. Written informed consent was obtained from the participants.

Results

Figure 1 and 2 show the configuration of PRISM discs performed by the patients. The comments provided by the participants are shown in the legends. The results from the applied questionnaires are shown in Table 2.

For patient 1, depression score indicated mild symptoms, and the level of anxiety was within

Figure 1. PRISM Configuration for Patient 1



Patient 1. "I have control, I like to know how my heart works. I am under medical care, which gives me power and the kind of sense that I know what's going on with me. I know I am ARh(-). ... And that such donor is not common. But...I have hope. It would be impossible to live without hope. I know my disease, I put up with it, but I don't accept it. That's why I'm fighting for a transplant. If I had accepted it, I wouldn't be fighting any more..."

Psychologist: "Would you like to place someone or something else important to you?"

Patient 1: "Can I choose the color? [smile]. I would add my wife, she's most important to me. I will choose the white disc for her. She must be somewhere close to me. And...understanding, which is vital for me. It is much easier when people close to you understand you. And when doctors understand what patients like me experience. Hmm....I like what I've done here [smile]. I can see that I am not alone."

Table 2. Results From the Applied Questionnaires

	Score (Maximum)	
	Patient 1	Patient 2
HADS depression	9	6
HADS anxiety	7	7
IPQ-R		
Timeline	24 (30)	12 (30)
Consequences	24 (30)	18 (30)
Personal control	21 (30)	23 (30)
Treatment control	18 (25)	18 (30)
Coherence	20 (25)	20 (30)
Timeline cyclical	14 (20)	14 (30)
Emotional response	18 (30)	14 (30)
Illness Cognition Questionnaire		
Helplessness	21 (24)	10 (24)
Acceptance	13 (24)	20 (24)
Perceived benefits	17 (24)	23(24)

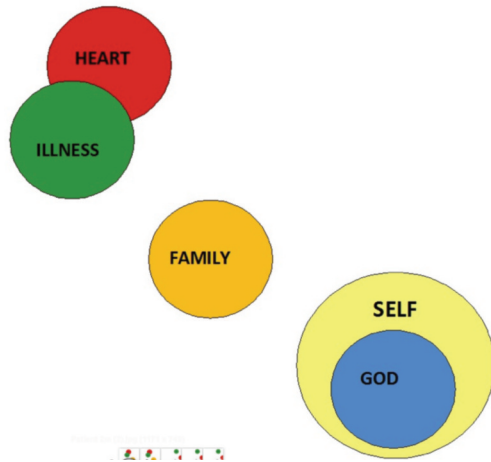
Abbreviations: HADS, Hospital Anxiety and Depression Scale; IPQ-R, Illness Perception Questionnaire Revised

normal level. Results suggest that the patient perceived the illness to be rather chronic, having severe consequences but at the same time controllable by treatment. He indicated that he understood it well and had control over it. He admitted that the illness brought positive value; nevertheless, the level of helplessness was high and illness acceptance remained low (Table 2).

For patient 2, both depression and anxiety scores were within normal levels. Illness Cognition Questionnaire results revealed low level of helplessness, high level of acceptance, and perceived benefits. The results from the IPQ-R measurement

indicated low emotional response to the illness. The patient perceived his illness as moderately controllable by treatment and short. He declared high illness coherence and perceived control. Attention should be paid to the high levels of hope and acceptance as well as the ability to benefit (Table 2).

Figure 2. PRISM Configuration for Patient 2



Patient 2. "Illness is the center of my life. And so is heart, because heart is 'the illness.' The illness is also in my family, because my wife is also severely ill. We support each other...we believe that there is hope and that God will help us...taking someone from this world and giving me his heart...I have faith in me. It's one of the most important aspects of my life. It's so helpful to think that everything will be ok. I also think I have control over my illness by visiting doctors regularly and taking pills. And in spring I will have a new heart! [smile]. I don't want it now, in winter. My wife would have a big problem..."

Discussion

By presenting the personal experiences of patients, we attempted to emphasize the psychological dimensions, which may not be fully appreciated in routine clinical care.² Exploring the factors of great importance to our patients enhances understanding of a patient's perspective, which may benefit in improved, multidimensional care. Undoubtedly, to our patients, being on heart transplant wait list and the illness itself are the dominating aspects of their lives. Being close to significant others is also of great importance. Interestingly, we can identify 2 conflicting areas when exploring the patient's perspective: on the one hand, the patients are aware of the somatic condition severity, unpredictability of the situation's progress, and inevitability of transplant, and they display a realistic cognitive picture of the disease. On the other hand, they declare a high level of perceived control over the illness, which seems to be related to their knowledge, compliance, and medical care. At the same time, the

patients seem to be aware of the extent to which their future depends on fate, destiny, or God. However, the overpowering hope related to force majeure, being beyond control, does not determine hopelessness and helplessness. The awareness and sense of control seem to be a part of the patients' autonomy, especially vital in terms of decision-making with regard to the heart transplant.^{4,12} Our results suggesting that hope, illness coherence, and perceived control favor a lower level of depression and anxiety are in accord with other authors' conclusions.¹³ Interestingly, one of the patients made a distinction between putting up with the illness and acceptance, the meaning of which has received attention in literature.⁵ In our patient's opinion acceptance means surrender. This observation proves the importance of defining terms to enhance patient-clinician communication.

Aside from the research aims, the usefulness of PRISM is worth mentioning. The patients' configurations expose the most important factors as the closest to the "self." By performing PRISM in nonstandard way and making patients choose and name the preferred elements of illness and life, we approached the essence of their experiences and facilitated sharing of their feelings. As studies have revealed, the application of PRISM seems to be valuable for diagnostic and therapeutic purposes, as well as a tool facilitating clinician-patient communications.⁸ Pictorial Representation of Illness and Self Measure may also make patients focus on positive aspects of experiencing a chronic disease, which can be helpful in going beyond the unfavorable perception of illness.⁵ It is also worth emphasizing that the use of both quantitative and qualitative methods allows more opportunities to explore a patient's perspective.¹⁴ One should realize the extent to which experiencing a chronic illness may be traumatic for the individual patient but also constitute the source of positive growth.⁸ Understanding a patient's perspective, respect for their hope and autonomy, and enhancing positive illness cognition may result in adaptable coping abilities, mental well-being, and treatment compliance.^{5,13,15}

References

1. Saczynski JS, Kiefe CI. Dawning of a New Era: understanding the functional outcomes of cardiovascular disease. *Circ Cardiovasc Qual Outcomes* 2014;7(6):812-814.

2. Cupples S, Dew MA, Grady KL, et al. Report of the Psychosocial Outcomes Workgroup of the Nursing and Social Sciences Council of the International Society for Heart and Lung Transplantation: Present status of research on psychosocial outcomes in cardiothoracic transplantation: review and recommendations for the field. *J Heart Lung Transplant*. 2006; 25(6):716-25. doi:10.1016/j.healun.2006.02.005.
3. Sutanto B, Singh-Grewal D, McNeil HP, et al. Experiences and perspectives of adults living with systemic lupus erythematosus: thematic synthesis of qualitative studies. *Arthritis Care Res*. 2013;65(11):1752-65.
4. Gulla B. [Psychological aspects of heart transplantation]. *Psychiatr Pol* 2006;40(2):323-334.
5. Evers AW, Kraaimaat FW, van Lankveld W, Jongen PJ, Jacobs JW, Bijlsma JW. Beyond unfavorable thinking: The Illness Cognition Questionnaire for chronic disease. *J Consult Clin Psychol*. 2001; 69(6):1026-1036.
6. Spaderna H, Mendell NR, Zahn D, et al. Social isolation and depression predict 12-month outcomes in the "waiting for a new heart study". *J Heart Lung Transplant*. 2010; 29(3):247-254.
7. Madan A, White-Williams C, Borckardt JJ, et al. Beyond rose colored glasses: the adaptive role of depressive and anxious symptoms among individuals with heart failure who were evaluated for transplantation. *Clin Transplant*. 2012; 26(3):E223-E231.
8. Büchi S, Sensky T. PRISM: Pictorial Representation of Illness and Self Measure. A brief nonverbal measure of illness impact and therapeutic aid in psychosomatic medicine. *Psychosomatics*. 1999; 40(4):314-320.
9. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; 67(6): 361-370.
10. Lauwerier E, Crombez G, Van Damme S, Goubert L, Vogelaers D, Evers AVM. The construct validity of the Illness Cognition Questionnaire: the robustness of the three-factor structure across patients with chronic pain and chronic fatigue. *Int J Behav Med*. 2010; 17(2):90-96.
11. Moss-Morris R, Weinman J, Petrie KJ, et al. The Revised Illness Perception Questionnaire (IPQ-R). *Psychol Health*. 2002; 17(1):1-16.
12. Reach G. Patient autonomy in chronic care: solving a paradox. *Patient Prefer Adherence*. 2013; 8: 15-24.
13. Kung M, Koschwanez HE, Painter L, Honeyman V, Broadbent E. Immunosuppressant nonadherence in heart, liver and lung transplant patients: Associations with medication beliefs and illness perceptions. *Transplantation*. 2012; 93(9):958.
14. Janelle C, O'Connor K, Dupuis G. Evaluating illness representations in heart transplant patients. *J Health Psychol*. 2015 Jan 27. pii: 1359105314567210. Epub ahead of print.
15. Massey EK, Tielen M, Laging M, et al. The role of goal cognition, illness perceptions and treatment beliefs in self-reported adherence after kidney transplantation: a cohort study. *J Psychosom Res*. 2013;75(3):229-234.