Illness identity: capturing the influence of illness on the person's sense of self

Liesbet Van Bulck^a, Koen Luyckx^{b,c}, Eva Goossens^{a,d,e}, Leen Oris^{b,d}, Philip Moons^{a,f,g}

^a KU Leuven Department of Public Health and Primary Care, KU Leuven - University of Leuven, B-3000 Leuven, Belgium

^b KU Leuven School Psychology and Development in Context, KU Leuven – University of Leuven, B-3000 Leuven, Belgium

^c UNIBS, University of the Free State, Bloemfontein, South Africa

^d Research Foundation Flanders (FWO), Brussels, Belgium

^e Division of Congenital and Structural Cardiology, University Hospitals Leuven, Leuven, Belgium

^f Institute of Health and Care Sciences, University of Gothenburg, Gothenburg, Sweden

^g Department of Paediatrics and Child Health, University of Cape Town, Cape Town, South Africa

Corresponding author:

Philip Moons, KU Leuven – University of Leuven, Kapucijnenvoer 35, Box 7001, B-3000 Leuven, Belgium. Email: philip.moons@kuleuven.be. Twitter: @MoonsPhilip

Having a heart condition can pose major challenges to a person's life, due to strict medication regimens, treatments, lifestyle changes, and often the uncontrollable or life-threatening nature of the condition.¹ Hence, patients with heart conditions may have trouble in dealing with their disease and incorporating it in their lives.

There is a vast body of literature on how people deal with their disease or illness. A critical element in this matter is how people look at and experience their illness. To date, most studies in this context have focused on investigating illness perceptions. This relatively well-

investigated concept pertains to the way patients perceive and think about their disease.² Articles that have been published in the *European Journal of Cardiovascular Nursing* have indicated that illness perceptions are associated with: quality of life³, performance of self-care⁴, adherence⁵, treatment-seeking behavior⁶, general healthcare use⁷, and attendance at cardiac rehabilitation programs⁸. Therefore, illness perceptions ought to be taken into account by nurses and allied healthcare professionals in the care for patients with acute and chronic cardiovascular conditions.

Another particularly interesting concept in this context is illness identity.⁹ Illness identity can be defined as “*the degree to which a chronic health condition, such as a heart disease, is integrated into someone’s identity*”.^{9,10} As compared to illness perceptions, illness identity not only expresses how a person views the disease and the treatment, but also how much the disease has affected the way they think about themselves and the degree to which the illness became integrated into one’s sense of self.⁹ The overarching framework of illness identity comprises four different constructs: *engulfment*, *rejection*, *acceptance*, and *enrichment* (see Figure 1).¹⁰ *Engulfment* indicates the degree to which patients feel that their disease dominates their identity.^{10,11} These patients completely define themselves in terms of their disease. Another construct pertaining to illness identity is *rejection*, which refers to the degree to which the disease is rejected as part of the patient’s identity and is seen as a threat or as unacceptable to the self.^{10,12} Patients with high rejection scores tend to refute their disease, which often results in suboptimal disease self-management and adherence.^{10,13} A more adaptive state of illness identity is *acceptance*, defined as the degree to which patients accept their disease as part of their identity aside from other self-defining identity assets, without being overwhelmed.¹⁰⁻¹² Hence, these patients try to lead a life, as normal as possible, in which they do not deny having a disease. Finally, *enrichment* is the fourth illness identity state. Some

people feel that their disease has changed their values and how they look on life and that their disease actually enabled them to grow as a person.^{10,14}

INSERT FIGURE 1 ABOUT HERE

To assess these different illness identity states, the Illness Identity Questionnaire has been recently developed.^{10,15} This self-report questionnaire comprises 25 items that measure the four illness identities by statements such as ‘My illness dominates my life’ (i.e., engulfment), ‘I just avoid thinking about my illness’ (i.e., rejection), ‘I am able to place my illness in my life’ (i.e., acceptance), and ‘Because of my illness, I have become a stronger person’ (i.e., enrichment). For each statement, patients can indicate how much they agree, using a 5-point Likert scale ranging from 1 (i.e., strongly disagree) to 5 (i.e., strongly agree).¹⁰ The questionnaire has been used for the first time and validated in patients with type 1 diabetes.¹⁰ In cardiac patients, the questionnaire has been employed in adults with congenital heart disease (CHD) and appeared to be reliable and valid in these patients.¹⁵

The latter study, performed in patients with CHD, showed that patients who felt engulfed, were more likely to perceive depressive and anxiety symptoms and physical symptoms of the heart disease, and were more likely to be hospitalized, and to visit a medical specialist or a general practitioner.^{15,16} A possible explanation is that patients who experience a lot of symptoms or those who are in high need for medical follow-up, feel more engulfed by the condition.^{15,16} However, it is also possible that patients who feel overwhelmed by their condition have a lower threshold to seek care.¹⁶ Since the latter study in patients with CHD used a cross-sectional research design, the directionality of these associations remains unknown.

Patients with CHD who presented with high rejection scores were found to have more physical symptoms of the heart disease.¹⁵ This is not surprising since suboptimal adherence, which is often a result from illness rejection, could lead to a deterioration of the condition and

could, subsequently, provoke symptoms. Again, an opposite directionality of effect is possible here as well, as the disease might be rejected from one's sense of self as a defense mechanism when patients experience more symptoms.¹⁷ In recent analyses, rejection was found to be related to absenteeism at work or school in adults with CHD.¹⁸

Moreover, patients who accepted their illness as part of their identity were found to have less depressive and anxiety symptoms, and less physical symptoms of their heart disease. It is believed that acceptance might enable patients to better deal with challenges of the disease, and that acceptance leads to better self-care behaviors.^{15,19} However, it could also be that experiencing few symptoms and pain might enhance acceptance, because the disease does not affect every day functioning.¹⁵

Finally, patients who felt enriched were found to have more physical symptoms of their heart disease.¹⁵ This can be explained by the fact that individuals have to experience a substantial impact of their disease in order to be able to grow as a person.¹⁴

To the best of our knowledge, no other studies about illness identity have been published in the domain of cardiology so far. A qualitative study about illness disruption in heart transplant recipients have been published, indicating that a disruption between the identity and the body occurred frequently after a heart transplant.²⁰ Illness disruption is related to illness identity, but does not cover the same constructs. Moreover, some studies have investigated the concept of illness acceptance in patients with cardiovascular conditions.²¹⁻²⁴ However, these studies rather investigated the adaption to the disease and did not specifically focus on the integration of the cardiac condition into the identity.

The first studies on illness identity in cardiac populations shows that it may be an important concept for cardiovascular nursing.^{15,16} However, the body of empirical evidence is currently scarce and is limited to investigations performed in patients with CHD. Future research about illness identity and the impact of illness identity on functioning in patient

populations with a diversity of cardiac conditions is needed. The scientific community should put studies focusing on illness identity on the research agenda, and researchers in cardiovascular nursing and allied professions may take up this interesting concept to improve our understanding of how a health condition, illness or disease is integrated in one's sense of self and life.

References

1. Jarbøl DE, Larsen PV, Gyrd-Hansen D, et al. Determinants of preferences for lifestyle changes versus medication and beliefs in ability to maintain lifestyle changes. A population-based survey. *Prev Med Rep* 2017; 6: 66-73.
2. Benyamini Y. Health and illness perceptions. In: Friedman HS (ed) *The Oxford handbook of health psychology*: Oxford University Press, 2011, pp.281-313.
3. Schoormans D, Mulder BJ, van Melle JP, et al. Illness perceptions of adults with congenital heart disease and their predictive value for quality of life two years later. *Eur J Cardiovasc Nurs* 2014; 13: 86-94.
4. MacInnes J. Relationships between illness representations, treatment beliefs and the performance of self-care in heart failure: a cross-sectional survey. *Eur J Cardiovasc Nurs* 2013; 12: 536-543.
5. Mosleh SM and Almalik MM. Illness perception and adherence to healthy behaviour in Jordanian coronary heart disease patients. *Eur J Cardiovasc Nurs* 2016; 15: 223-230.
6. MacInnes JD. The illness perceptions of women following symptoms of acute myocardial infarction: a self-regulatory approach. *Eur J Cardiovasc Nurs* 2006; 5: 280-288.
7. Schoormans D, Sprangers MA, van Melle JP, et al. Clinical and psychological characteristics predict future healthcare use in adults with congenital heart disease. *Eur J Cardiovasc Nurs* 2016; 15: 72-81.

8. Blair J, Angus NJ, Lauder WJ, et al. The influence of non-modifiable illness perceptions on attendance at cardiac rehabilitation. *Eur J Cardiovasc Nurs* 2014; 13: 55-62.
9. Charmaz K. The body, identity, and self: Adapting to impairment. *Sociol Q* 1995; 36: 657-680.
10. Oris L, Rassart J, Prikken S, et al. Illness Identity in Adolescents and Emerging Adults With Type 1 Diabetes: Introducing the Illness Identity Questionnaire. *Diabetes care* 2016; 39: 757-763.
11. Morea JM, Friend R and Bennett RM. Conceptualizing and measuring illness self-concept: a comparison with self-esteem and optimism in predicting fibromyalgia adjustment. *Res Nurs Health* 2008; 31: 563-575.
12. Adams S, Pill R and Jones A. Medication, chronic illness and identity: the perspective of people with asthma. *Soc Sci Med* 1997; 45: 189-201.
13. Tilden B, Charman D, Sharples J, et al. Identity and adherence in a diabetes patient: transformations in psychotherapy. *Qual Health Res* 2005; 15: 312-324.
14. Helgeson VS, Reynolds KA and Tomich PL. A meta-analytic review of benefit finding and growth. *J Consult Clin Psychol.* 2006; 74: 797-816.
15. Oris L, Luyckx K, Rassart J, et al. Illness Identity in Adults with a Chronic Illness. *J Clin Psychol Med Settings*. Epub ahead of print 21 February 2018. DOI: 10.1007/s1088001895520.
16. Van Bulck L, Goossens E, Luyckx K, et al. Illness Identity: A Novel Predictor for Healthcare Use in Adults With Congenital Heart Disease. *J Am Heart Assoc* 2018; 7: e008723.
17. Mozzetta A, Antinone V, Alfani S, et al. Mental health in patients with systemic sclerosis: a controlled investigation. *J Eur Acad Dermatol Venereol* 2008; 22: 336-340.

18. Van Bulck L, Luyckx K, Goossens E, et al. Illness Identity and Its Association With Absence at Work or School in Adults With Congenital Heart Disease. *Circulation* 2018 (in press).
19. Luyckx K, Vanhalst J, Seiffge-Krenke I, et al. A typology of coping with Type 1 diabetes in emerging adulthood: associations with demographic, psychological, and clinical parameters. *J Behav Med* 2010; 33: 228-238.
20. Mauthner OE, De Luca E, Poole JM, et al. Heart transplants: Identity disruption, bodily integrity and interconnectedness. *Health (London)* 2015; 19: 578-594.
21. Obieglo M, Siennicka A, Jankowska EA, et al. Direction of the Relationship Between Acceptance of Illness and Health-Related Quality of Life in Chronic Heart Failure Patients. *J Cardiovasc Nurs* 2017; 32: 348-356.
22. Guck TP, Kinney M, Anazia G, et al. Relationship between acceptance of illness and functional outcomes following cardiac rehabilitation. *J Cardiopulm Rehabil Prev* 2012; 32: 187-191.
23. Karademas EC. Illness cognitions as a pathway between religiousness and subjective health in chronic cardiac patients. *J Health Psychol* 2010; 15: 239-247.
24. Karademas EC, Tsagaraki A and Lambrou N. Illness acceptance, hospitalization stress and subjective health in a sample of chronic patients admitted to hospital. *J Health Psychol* 2009; 14: 1243-1250.

Figures

Figure 1. Visualisation of the four illness identity constructs

Legend. The dot represents the heart disease and the circle represents identity.