RESILIENCE AND ILLNESS DENIAL AS PREDICTING FACTORS FOR ADHERENT BEHAVIOUR

Gunita Skaldere-Darmudasa

Rīga Stradiņš University, Latvia

Velga Sudraba

Department of Health psychology and paedagogy, Rīga Stradiņš University, Latvia

Abstract. Lack of adherence in patients with chronic illnesses is significant burden for health care system all over the world. Therefore, it is important to find which factors do contribute to improve adherent behaviour. The aim of this study was to find out how resilience and illness denial predicts adherent behaviour in patients with chronic illnesses in primary health care. In this quantitative cross-sectional study participated 202 adults in Latvia with diagnosed chronic illness. Participants filled sociodemographic data questionnaire – gender, age, and diagnosis, Connor-Davidson Resilience Scale (CD-RISC-25, Connor & Davidson, 2003), Illness Denial Questionnaire-Short Form (IDQ-SF, Rossi Ferrario et al., 2019), and Adherent behaviour questionnaire (Skaldere-Darmudasa & Sudraba, 2023) – nine items measure assessing to what extent individual with chronic illness follows doctor's or specialist's recommendation to reduce symptoms of their chronic illness and improve health condition. *Items are rated in 4 – point Likert scale. The result of this study shows a tendency that patients* with chronic illness and higher resilience use less denial according to their chronic illness and use more adherent behaviour. Higher denial points to less adherent behaviour which means less following to the doctor's and specialist's recommendation about the intake of medication, physical activities, diet, and rest.

Keywords: adherence, adherent behaviour, chronic disease/illness, compliance, illness denial, resilience.

Introduction

Adherence is the fundamental need in patients experiencing chronic illness to maintain their health. Empirical evidence shows that 50 % of patients are not adherent and less than 30 % of patients follow the doctor's recommendations regarding the intake of their medication (Claxton, Cramer, & Pierce, 2001; Osterberg & Blaschke, 2005). According to World Health Organization (WHO), less adherent are patients with chronic illnesses, because mostly they stop the intake of medication after reducing acute symptoms (Claxton, Cramer, & Pierce, 2001; Osterberg & Blaschke, 2005). Low adherence raises the risk of repeated

hospitalization, worse illness outcome, complicated treatment and higher health costs (Iuga & McGuire, 2014; Sokol, McGuigan, Verbrugge, & Epstein, 2005). Such situation leads to multiple factors interaction which are affecting the adherence, and there is not enough explanation within existing theories which factors contribute more to adherent behaviour (Holmes, Hughes, & Morrison, 2014). Therefore, as psychological factors in patients with chronic illnesses might be illness denial (Ballantyne, 2007; Sabate, 2003) and low resilience (Goldanimoghadam, Asghari, & Manee, 2019). The aim of this study was to find out how resilience and illness denial predicts adherent behaviour in patients with chronic illness in primary health care.

Theoretical basis of the problem

Adherence and adherent behaviour

Adherence is the ability of the individual to follow the specialist's recommended treatment regime especially the intake of medication (APA, 2022). Low adherence depends on many individual factors such as individual cognitive abilities, unbearable, disturbing side effects of medication, several psychological aspects facing the illness, specific illness related factors, and social and financial factors (Delgado, 2016). Many authors have agreed that reasons for low adherence could be related to patients and it's families limited understanding about the illness and illness denial, low social support, financial and household related difficulties (Fischer et al., 2010; Peterson, Takiya, & Finley, 2003). Low adherence results with low efficiency of treatment, worse outcome of the illness, it raises the risk of comorbidities and death cases. It is a burden for the health care system because rising costs for health care (Anghel, Farcas, & Oprean, 2019; Cheen, Tan, Oh, Wee, & Thumboo, 2019).

There is not enough instruments and strategies how to raise and promote adherence in patients, therefore, it is necessary to study adherence to gain knowledge which could promote adherence (Lieber, Helcer, & Shemesh, 2015). Regarding the promotion of adherence – psychology plays a significant role using psychological techniques in practice to invent new interventions to promote adherent behaviour and the outcome of the illness in future (Bosworth, Blalock, Hoyle, Czajkowski & Voils, 2018). Adherent behaviour within this study is set of certain activities regarding patients' health management including following doctors recommendations – intake of medication, health monitoring, and healthy lifestyle according to patients abilities and limitations (Skaldere-Darmudasa & Sudraba, 2023).

Resilience in patients with chronic illnesses

In recent years, the resilience has become more popular in discussions regarding health in society. Research of resilience has focused on fundamental factors which makes individual strong to face difficult life challenges – to be able to use adaptive strategies in order to return to stable psychoemotional state of mind after adverse event. The research focuses on necessity to identify these factors and ways of how to promote resilience. Resilience is a multidimensional construct being affected by the individual's biopsychosocial factors. Resilience is related with quality of life (Liu, Xu, Xu, & Wang, 2017; Bottolfs et al., 2020), but more significant is this relationship for patients with chronic illness who are exposed to more difficulties in their everyday life. Chronic illness demands time, expenses and is not fully treatable.

In systematic review about resilience in patients with chronic illness it is stated that resilience is affecting the process and outcome of the illness (Cal, Sá, Glustak, & Santiago, 2015). In other systematic review authors agree that it is possible to promote and train the resilience regardless of the period of life time when experiencing the illness and illness severity. Resilience is related to adherence and well-being (Gheshlagh et al., 2016).

The authors (Cannon, Sriram, Liew & Sun, 2018) have identified individual and contextual factors of resilience which contributes to well-being in stressful situations for patients with chronic obstructive lung disease. Three main factors regarding resilience were highlighted: (1) patient's individual factors (selfesteem, self-efficiency, and coping strategies); (2) patient's contextual factors (accessible support system including support from family, friends and health care specialists); (3) environmental factors (including relationships, cultural identity, available facilities), (Cannon, Sriram, Liew & Sun, 2018). The same factors contributing resilience could be applied to other patients with chronic illness who are affected by individual, contextual and environmental factors.

In samples of patients who had myocardial infarction (N=234) higher resilience served as a condition for better mental health, reduced risk of repeated hospitalization, lower anxiety and depression symptoms, regardless of other clinical, sociodemographic and psychosocial factors (Toukhsati et al., 2020).

Illness denial

It is a difficult challenge in psychological, emotional and physical way facing chronic illness. Not always everyone is able to react adequately to such adverse event, what can result in choosing maladaptive coping strategies to overcome distress. One of the maladaptive response could be illness denial. Illness denial is an unaware defence mechanism which protects the mind from distress (Cramer,

2000). Illness denial includes denial of negative emotions and resistance to change (Rossi Ferrario et al., 2019).

Significant contribution to research of illness denial is done by American psychologist Hanoch Livneh (Livneh, 2009). He has described different views of earlier authors like Isabelle Kendig (1963) noting that belief of body and mind unity contributes to good health, Joel Dimsdale and Thomas Hackett (1982) postulated that illness denial can be aware or unaware denial of available knowledge about illness to reduce anxiety and emotional distress. Hanoch Livneh has studied definitions of illness denial which includes three perspectives: (1) psychodynamic (denial is defence mechanism or strategy to overcome distress); (2) cognitive (denial is distortion of reality); (3) organic (denial is neurological distortion – anosognosia). All definitions of the denial include elements of concept of denial such as protecting individual from anxiety and perceived threat, reducing pressure of reality, tendency to deny or destroy unwanted reality and its' impact, which is related to unwanted consequences related to chronic illness or gained disability (Livneh, 2009).

According to classic stress theory of American psychologist Richard Lazarus denial is used to reduce distress (Lazarus & DeLongis, 1983). Therefore, partial denial in early phase of chronic illness would serve as process of adaptation if used appropriately (White et al, 2016). White and colleagues (White et al., 2016) have described that in earlier studies authors (Lazarus & DeLongis, 1983; Lazarus & Folkman, 1986) define two types of denial: (1) illness denial – totally denying existence of illness and (2) denial of impact – denying that existing illness might affect or limit individual abilities in different life activities. Regardless the type of denial the individual might use, in short period of time it can protect the individual from distress, but in longer period of time cause harm to the individual's health (White et al, 2016).

Illness impact denial was negatively correlated with anxiety and depression in sample of patients (N=80) with congenital heart disease. This shows that denial of illness impact serves as psychological defence mechanism. In this study illness impact denial was related with higher individual perceived general health (White et al, 2016). In qualitative studies in patients with newly diagnosed rheumatoid arthritis, many patients showed high illness denial which led to difficulties to follow treatment regime and intake of medication. Illness denial was related to negative perception of intake "strong and harmful" medication and general disappointment that the body is losing some of its' abilities (Oshotse, Zullig, Bosworth, Tu, & Lin, 2018).

Illness denial plays a negative role in communication between oncological patients, their families, and specialists. Illness denial in patients and their families

is related with specialists perceived efficiency. The specialist feels less efficient and helpless to deliver good care for patients if patients and its' family are experiencing denial (Pene & Kissane, 2019).

Materials and Methods

In this quantitative cross-sectional study participated 202 respondents in Latvia with diagnosed chronic illness (duration of the illness is more than one year, National Centre for Chronic Disease Prevention and Health Promotion, 2022), of which 73 % were females (n=147). Participants were in age from 22 to 65 years old (M=53.40; SD=11.08). Including criteria were knowledge of Latvian language, diagnosed chronic illness, belonging to age group from 18 to 65 years old.

Measures

Sociodemographic data and illness related data – age, gender, diagnosis.

Connor-Davidson Resilience Scale (CD–RISC–25), (Connor & Davidson, 2003), (α = .89). Adaptation in Latvian language is done by Skaldere-Darmudasa & Sudraba (2021). The 25 item self-assessment measure using Likert scale from 0 to 4, where 0 - not true at all, 1- rarely true, 2 – sometimes true, 3 – often true, 4 – true nearly all the time. The total result of resilience could vary from 0 to 100, higher scores reflecting higher resilience. Due to recommendations from authors of the scale, the result of resilience is total score of the scale.

Illness denial Questionnaire-Short Form (IDQ-SF, Rossi Ferrario et al., 2019). Adaptation in Latvian language was carried out by Skaldere-Darmudasa & Sudraba (2023) within masters' thesis. This eight item self-assessment measure ($\alpha = .76$) includes two factor structure: (1) denial of negative emotions, (2) resistance to change. The items are evaluated in dichotomus categories with answer *yes* scoring 1 point, *no* – scoring 0 points. Higher result reflects to higher denial towards one's illness.

Adherent Behaviour Questionnaire (Skaldere-Darmudasa & Sudraba, 2023), ($\alpha = .75$). This nine-item self-assessment measure was created within master's thesis and measure to what extent the individual follows the specialist's recommendations regarding the reduce symptoms of chronic illness and improved health condition. The measure includes three subscales: (1) intake of medication; (2) health monitoring; (3) healthy lifestyle. Items are rated by Likert's scale from 1 to 4 (1 – never, 2 – sometimes, 3 – often, 4 - always). Higher result reflects the higher adherent behaviour.

The data were collected in both – paper and electronical form using platform www.visidati.lv. Several general practice doctors, specialists and patient organization ("Dzīvības koks"- www.dzivibaskoks.lv, "Par sirdi" – www.parsirdi.lv) were involved in collecting the data. The specialists and patient organizations distributed survey to their patients. Part of the surveys were

collected in paper format. The paper format surveys were destroyed after entering them in computer.

Ethical aspects and personal data protection

Data collection and protection was performed according to rules of European Parliament regalement number (ES) 2016/679 about personal data protection and processing. Participants were introduced with Informed consent which included information about participation in study, research aim and process. Participation was voluntary without reward. Data are anonymous and was processed with confidentiality. Permission to carry out the study was given and confirmed by Research Ethical Committee of Riga's Stradi, Stradi, University issuing permit no. 2-PEK-4/108/2022.

Data analysis

Data processing was carried out using MS Office Excel, IBM SPSS 27.0 programs. Nonparametric method was chosen because data was not normally distributed. Correlations were assessed using Spearmen's correlation analysis. All results with statistical significance p < .05 are discussed. Predicting impact was analysed using multiple linear regression analysis.

Results

There is statistically significant negative correlation between illness denial and resilience ($r_s = -.41$, p < .001), and statistically significant low correlation between adherent behaviour and resilience ($r_s = .18$, p = .009). Adherent behaviour and illness denial showed statistically significant negative correlation ($r_s = -.17$, p = .01), (see Table 1).

	1.	2.	3.	
1. Resilience	_	_	_	
2. Illness denial	41^{**}	_	_	
3. Adherent behaviour	.18**	17*	_	
<i>Note</i> . N=202, ** <i>p</i> < .001, * <i>p</i> < .05				

 Table 1 Resilience, illness denial and adherent behaviour correlations in patients with chronic illnesses (created by the authors)

To analyse how resilience and illness denial predict adherent behaviour the multifactor linear regression analysis was carried out. In the model where resilience and illness denial were independent variable and adherent behaviour as dependent variable results shows that only resilience statistically significant (p=.02) predicts adherent behaviour $(R^2 = .04, F(1,199) = 7.39, p = .007)$ explaining 4 % of adherent behaviour variation (see Table 2).

Table 2 Multiple linear regression analysis with resilience and illness denial asindependent variables (created by the authors)

Independent variable	В	R^2	F
Resilience	0,17**	0,04	3,80**
Illness denial	-0,10	0,01	2,28

Note. N = 202, ***p* < .001.

Discussion

The aim of this study was to find out how resilience and illness denial predicts adherent behaviour in patients with chronic illnesses in primary health care. Based on literature review within this study (Ballantyne, 2007; Sabate, 2003; Goldanimoghadam, Asghari, & Manee, 2019; White et al, 2016; Catalán et. al., 2021), also this study shows similar results demonstrating that resilience and illness denial is related to adherent behaviour. Results of this study showed statistically significant negative correlation between illness denial and resilience, which means if patient has more difficulties to manage his or her illness higher is the denial – lower is his or her resilience – ability to choose adaptive strategies to live with chronic illness. Low resilience in patients with chronic illness leads to higher illness denial. There was statistically significant negative correlation between illness denial and adherent behaviour. Which explains that patients with higher denial about their illness are not able to implement adherent behaviour to manage their health condition and improve their chronic illness outcome. But statistically significant correlation between resilience and adherent behaviour explains that patients with higher resilience can better implement adherent behaviour in their life which will contribute to better chronic illness outcome (Catalán, Crisóstomo, Santamaría, Sainz, Valverde, & Jaimes, 2022; Escobar Florez, Aquilera, De la Roca-Chiapas, Cervantes, & Garay-Sevilla, 2021; White et al., 2016).

Authors (Anghel, Farcas, & Oprean, 2019) have postulated that improving adherence is higher evaluated than invention of new methods of treatment. (Anghel, Farcas & Oprean, 2019). Therefore, the aim of the study was to find out how resilience and illness denial predicts adherent behaviour. The multiple linear regression analysis showed that only resilience predicts adherent behaviour explaining 4 % of adherent behaviour variation. Such a result proves the multidimensional nature of all three constructs. Also, it could be different combinations of correlations between these variables in different samples depending on diagnosis. Results in this study are applicable only to this sample.

Therefore, in future studies to gain more specific and objective results in research of resilience, illness denial and adherent behaviour - it would be necessary to assess these variables in lager samples of patients with chronic illness, also within one diagnosis and take in account other sociodemographic factors.

Conclusions

The results of this study show tendencies that patients with higher resilience use less denial about their chronic illness and implement more adherent behaviour. Higher illness denial, which includes denial of negative emotions and resistance to change leads to less adherent behaviour, which means not following the specialist's recommendation regarding the intake medication, health monitoring and healthy lifestyle – less care for themselves. Resilience predicts adherent behaviour explaining 4 % of its' variation.

Limitations

As the limitations are self-assessment measures which could lead to more socially desirable answers. Part of the data was collected at a medical institution which means that these respondents are already more adherent and do not represent situation in population of patients with chronic illness. The sample of the study was heterogenous – it included different diagnoses and wider range of age. There could be other important sociodemographic factors contributing to results which were not analysed within this study.

References

- American Psychological Association (APA). (2022). *Adherence*. Retrieved from: https://dictionary.apa.org/adherence
- Anghel, L. A., Farcas, A. M., & Oprean, R. N. (2019). An overview of the common methods used to measure treatment adherence. *Medicine and pharmacy reports*, 92(2), 117–122. DOI: https://doi.org/10.15386/mpr-1201
- Ballantyne J. C. (2007). Opioid analgesia: perspectives on right use and utility. *Pain physician*, 10(3), 479–491.
- Bosworth, H. B., Blalock, D. V., Hoyle, R. H., Czajkowski, S. M., & Voils, C. I. (2018). The role of psychological science in efforts to improve cardiovascular medication adherence. *The American psychologist*, 73(8), 968–980. DOI: https://doi.org/10.1037/amp0000316
- Bottolfs, M., Støa, E. M., Reinboth, M. S., Svendsen, M. V., Schmidt, S. K., Oellingrath, I. M., & Bratland-Sanda, S. (2020). Resilience and lifestyle-related factors as predictors for health-related quality of life among early adolescents: a cross-sectional study. *The Journal of international medical research*, 48(2), 300060520903656. DOI: https://doi.org/10.1177/0300060520903656

- Cannon, D. L., Sriram, K. B., Liew, A. W., & Sun, J. (2018). Resilience Factors Important in Health-Related Quality of Life of Subjects With COPD. *Respiratory care*, 63(10), 1281– 1292. DOI: https://doi.org/10.4187/respcare.05935
- Cal, S. F., Sá, L. R. D., Glustak, M. E., & Santiago, M. B. (2015). Resilience in chronic diseases: A systematic review. *Cogent Psychology*, 2(1), 1024928.
- Catalán, G. M., Crisóstomo, Y. M., Santamaría, Y. R., Sainz, J. L. H., Valverde, J. M. G., & Jaimes, J. A. P. (2021). Stages of Grief and Therapeutic Adherence in People with Type 2 Diabetes Mellitus. *Atención Familiar*, 28(3), 162–166.
- Cheen, M. H. H., Tan, Y. Z., Oh, L. F., Wee, H. L., & Thumboo, J. (2019). Prevalence of and factors associated with primary medication non-adherence in chronic disease: A systematic review and meta-analysis. *International journal of clinical practice*, 73(6), e13350. DOI: https://doi.org/10.1111/ijcp.13350
- Claxton, A. J., Cramer, J., & Pierce, C. (2001). A systematic review of the associations between dose regimens and medication compliance. *Clinical therapeutics*, *23*(8), 1296-1310.
- Cramer P. (2000). Defense mechanisms in psychology today. Further processes for adaptation. *The American psychologist*, 55(6), 637–646. DOI: https://doi.org/10.1037//0003-066x.55.6.637
- Davidson, J. M., (2003). Connor-Davidson Resilience Scale (CD-RISC) Manual. Unpublished. 06-01-2020. Retrieved from: www.cd-risc.com
- Delgado, S. V. (2016) Non-Adherence to Treatment: Different Rules for Different Patients. *Arch Fam Med GenPract, 1*(1),12–17.
- Escobar Florez, O. E., Aquilera, G., De la Roca-Chiapas, J. M., Macías Cervantes, M. H., & Garay-Sevilla, M. E. (2021). The Relationship Between Psychosocial Factors and Adherence to Treatment in Men, Premenopausal and Menopausal Women with Type 2 Diabetes Mellitus. *Psychology research and behavior management*, *14*, 1993–2000. DOI: https://doi.org/10.2147/PRBM.S342155
- Fischer, M. A., Stedman, M. R., Lii, J., Vogeli, C., Shrank, W. H., Brookhart, M. A., & Weissman, J. S. (2010). Primary medication non-adherence: analysis of 195,930 electronic prescriptions. *Journal of general internal medicine*, 25(4), 284–290. DOI: https://doi.org/10.1007/s11606-010-1253-9
- Gheshlagh, R. G., Sayehmiri, K., Ebadi, A., Dalvandi, A., Dalvand, S., & Tabrizi, K. N. (2016). Resilience of patients with chronic physical diseases: A systematic review and metaanalysis. *Iranian Red Crescent Medical Journal*, 18(7), 9.
- Goldanimoghadam, Z., Asghari, B. A., & Manee, M. F. (2019). Relationship between resilience with illness behavior in dialysis patients. *Journal of Research and Health*, 9(3), 203–211.
- Holmes, E. A., Hughes, D. A., & Morrison, V. L. (2014). Predicting adherence to medications using health psychology theories: a systematic review of 20 years of empirical research. Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research, 17(8), 863–876. DOI: https://doi.org/10.1016/j.jval.2014.08.2671
- Iuga, A. O., & McGuire, M. J. (2014). Adherence and health care costs. *Risk management and healthcare policy*, 7, 35.
- Lazarus, R. S., & DeLongis, A. (1983). Psychological stress and coping in aging. *American* psychologist, 38(3), 245.
- Lieber, S. R., Helcer, J., & Shemesh, E. (2015). Monitoring drug adherence. *Transplantation Reviews*, 29(2), 73–77.
- Liu, L., Xu, X., Xu, N., & Wang, L. (2017). Disease activity, resilience and health-related quality of life in Chinese patients with rheumatoid arthritis: a multi-center, cross-sectional

study. *Health and quality of life outcomes*, 15(1), 149. DOI: https://doi.org/10.1186/s12955-017-0725-6

- Livneh, H. (2009). Denial of chronic illness and disability: Part I. Theoretical, functional, and dynamic perspectives. *Rehabilitation Counseling Bulletin*, *52*(4), 225–236.
- National Center for Chronic Disease Prevention and Health Promotion (2022). About Chronic Diseases. https://www.cdc.gov/chronicdisease/about/index.htm [seen on 28.11.2022.].
- Oshotse, C., Zullig, L. L., Bosworth, H. B., Tu, P., & Lin, C. (2018). Self-Efficacy and Adherence Behaviors in Rheumatoid Arthritis Patients. *Preventing chronic disease*, 15, E127. DOI: https://doi.org/10.5888/pcd15.180218
- Osterberg, L., & Blaschke, T. (2005). Adherence to medication. *The New England journal of medicine*, 353(5), 487–497. DOI: https://doi.org/10.1056/NEJMra050100
- Pene, C. T. H., & Kissane, D. (2019). Communication in cancer: its impact on the experience of cancer care: communicating with the angry patient and the patient in denial. *Current* opinion in supportive and palliative care, 13(1), 46–52. DOI: https://doi.org/10.1097/SPC.00000000000410
- Peterson, A. M., Takiya, L., & Finley, R. (2003). Meta-analysis of trials of interventions to improve medication adherence. *American journal of health-system pharmacy : AJHP :* official journal of the American Society of Health-System Pharmacists, 60(7), 657–665. DOI: https://doi.org/10.1093/ajhp/60.7.657
- Rossi Ferrario, S., Giorgi, I., Baiardi, P., Giuntoli, L., Balestroni, G., Cerutti, P., Manera, M., Gabanelli, P., Solara, V., Fornara, R., Luisetti, M., Omarini, P., Omarini, G., & Vidotto, G. (2017). Illness denial questionnaire for patients and caregivers. *Neuropsychiatric disease and treatment*, 13, 909–916. DOI: https://doi.org/10.2147/NDT.S128622
- Rossi Ferrario, S., Panzeri, A., Anselmi, P., & Vidotto, G. (2019). Development and psychometric properties of a short form of the Illness Denial Questionnaire. *Psychology research and behavior management*, *12*, 727–739. DOI: https://doi.org/10.2147/PRBM.S207622
- Sabaté, E., & Sabaté, E. (2003). *Adherence to long-term therapies: evidence for action*. World Health Organization.
- Skaldere-Darmudasa, G., & Sudraba, V., (2023). Psiholoģiskā noturība un slimības noliegšana kā līdzestīgu uzvedību prognozējošoie faktori hroniski slimiem pacientiem primārā aprūpē. Maģistra darbs, RSU.
- Sokol, M. C., McGuigan, K. A., Verbrugge, R. R., & Epstein, R. S. (2005). Impact of medication adherence on hospitalization risk and healthcare cost. *Medical care*, 43(6), 521–530. DOI: https://doi.org/10.1097/01.mlr.0000163641.86870.af
- Toukhsati, S., Xu, K., Nasarudin, A., Caruso, K., Smith, S., Halim, J., ... & Hare, D. (2020). Psychological Resilience Protects Against All-Cause Unplanned Hospital Readmissions Following Acute Myocardial Infarction. *Heart, Lung and Circulation*, 29, S326.
- White, K. S., Pardue, C., Ludbrook, P., Sodhi, S., Esmaeeli, A., & Cedars, A. (2016). Cardiac denial and psychological predictors of cardiac care adherence in adults with congenital heart disease. *Behavior modification*, 40(1-2), 29–50.