



City Research Online

City, University of London Institutional Repository

Citation: Hurt, C. S., Burn, D. J., Hindle, J. V., Samuel, M., Wilson, K. C. & Brown, R. G. (2014). Thinking positively about chronic illness: An exploration of optimism, illness perceptions and well-being in patients with Parkinson's disease. *British Journal of Health Psychology*, 19(2), pp. 363-379. doi: 10.1111/bjhp.12043

This is the unspecified version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/3589/>

Link to published version: <https://doi.org/10.1111/bjhp.12043>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

Thinking positively about chronic illness: An exploration of optimism, illness perceptions and well-being in patients with Parkinson's disease

Hurt CS¹, Burn DJ², Hindle J³, Samuel M⁴ Wilson K⁵ and Brown RG⁶

¹ City University London, School of Health Sciences, London, UK

² Institute for Ageing and Health, Newcastle University, Newcastle upon Tyne, UK

³ Llandudno Hospital, Department of Care of the Elderly, Llandudno and University of Bangor, School of Medical Sciences, UK

⁴ King's College Hospital, Department of Neurology, King's Health Partners, London, United Kingdom and East Kent Hospitals NHS University Foundation Trust, Ashford, Kent, UK

⁵ EMI Academic Unit, University of Liverpool, St Catherine's Hospital, Birkenhead, Wirral, UK

⁶ King's College London, Institute of Psychiatry, Department of Psychology, King's Health Partners, London UK

Word count (exc. figures/tables): 4514

*Requests for reprints should be addressed to Dr Catherine Hurt, City University London, School of Health Sciences, Health Services Research, Tait Building C329, Northampton Square, London EC1V 0HB. Email: Catherine.hurt.1@city.ac.uk.

Acknowledgements

Parkinson's UK; NIHR Biomedical Research Centre for Mental Health at the South London and Maudsley NHS Foundation Trust (SLaM) and Institute of Psychiatry, King's College London; NIHR Dementias and Neurodegenerative Diseases Research Network (DeNDRoN); Wales Dementias and Neurodegenerative Diseases Research Network (NEURODEM Cymru); NIHR Mental Health Research Network (MHRN); British Geriatrics Society.

Thinking positively about chronic illness: An exploration of optimism, illness perceptions and well-being in patients with Parkinson's disease

Abstract

Objectives

Holding positive beliefs about illness and having an optimistic outlook has been associated with increased well-being across a range of health conditions. However research has indicated that being very optimistic may not actually be beneficial and holding a realistic attitude is more adaptive in some forms of chronic illness, e.g. Parkinson's disease (PD). The present study aimed to explore the nature of relationships between illness perceptions, optimism and well-being; specifically whether a linear or non-linear relationship best described the data. Additionally the proposed moderating effect of optimism on the relationship between illness perceptions and well-being was tested.

Design

109 participants with idiopathic PD completed questionnaire measures of illness perception, optimism, mood and health-related quality of life (HRQoL).

Methods

Multiple regression analyses were used to explore relationships between illness perceptions, optimism, mood and HRQoL. The potential curvilinear effects of illness perceptions and optimism were modelled using squared variables and linear and quadratic curve estimation.

Results

Holding positive illness perceptions predicted better well-being. Some evidence for a non-linear relationship between optimism and mood was found. Optimism had a significant moderating effect on the relationship between specific illness perceptions and outcome.

Conclusions

Optimism appears to provide protection against some negative perceptions of illness and was associated with better mood and HRQoL. The findings indicate which specific illness perceptions may be beneficial targets for therapy. Therapeutic interventions should focus on enhancing positive perceptions of PD but potentially more importantly general optimistic attitude to maximise well-being.

Key words: Optimism, illness perceptions, depression, anxiety, quality of life, Parkinson's disease

Introduction

Social cognition models of illness belief, specifically Leventhal's (1984) Common Sense Model of Illness Perception (CSM), are increasingly being used to explain adjustment to chronic illness e.g. (Groarke, Curtis, Coughlan, & Gsel, 2004; Jopson & Moss-Morris, 2003; Kaptein et al., 2008; Petrie, Jago, & Devcich, 2007). According to the CSM individuals hold a range of beliefs regarding their illness which influence coping strategies and ultimately physical and mental well-being. Indeed robust linear relationships between illness perceptions and a range of physical and mental health outcomes have been demonstrated in a number of conditions (Hagger & Orbell, 2003). Perceiving an illness as having serious consequences, holding a strong illness identity i.e. attributing many symptoms to the illness, and perceiving the illness to have a chronic timeline all correlate negatively with physical and mental health outcomes while strong beliefs that an illness can be controlled or cured show strong positive correlations. Illness perceptions are condition specific beliefs shaped by our knowledge, experiences and personal characteristics (Leventhal et al., 2003).

Contrastingly, optimism is a dispositional trait rather than illness specific, which has also been associated with good physical and mental health outcomes. Optimism is thought to buffer the effects of stress caused by chronic illness, bringing about positive well-being (Gustavsson-Lilius, Julkunen, Keskivaara, Lipsanen, & Hietanen, 2012). As a personality trait and a marker of an individual's general outlook on life which may influence perceptions of health and illness, we would expect to find relationships in a similar direction between optimism and health outcomes as seen between illness perceptions and outcome. However recent work has suggested that the relationship between optimism and outcome may actually be non-linear. In Parkinson's disease (PD), patients with 'marked' or 'very high' optimism have reported less use of adaptive coping strategies and do not seem to derive any extra benefit in terms of psychological well-being than patients displaying medium levels of optimism (de Ridder, Schreurs, & Bensing, 2000). It is hypothesised that being very optimistic may prevent patients from taking appropriate action to improve their well-being (de

Ridder et al., 2000). Consequently it can be assumed that marked optimism may not necessarily be adaptive for patients who have chronic, degenerative conditions.

As with optimism, is it possible to hold perceptions of illness that are unrealistically positive and are these perceptions maladaptive and therefore associated with poorer outcomes? A number of the dimensions of illness belief proposed in the CSM have the potential to be 'unrealistically positive' with reference to chronic diseases. Patients' who perceive few consequences of chronic, degenerative illness, have strong beliefs in their ability to control or cure their illness (through personal means or medication) or perceive their illness to be acute and likely to remit in the near future could be viewed as holding unrealistically positive perceptions. A recent qualitative study exploring patients' beliefs about PD provides some preliminary evidence for this claim. Patients who reported having a positive reaction to diagnosis (e.g. relief that PD was not life threatening) and believed actually that PD would have minimal impact on their lives were found to be depressed at a later stage in the disease (Hurt, Weinman, Lee, & Brown, 2012). It is hypothesised that these patients were unrealistically positive about the consequences of having PD and then found adjusting to the inevitable physical and social limitations harder than those who were less positive at the time of diagnosis.

Other research has suggested that optimism acts as a moderator between illness perceptions and well-being. Marked optimism has been argued to protect against the effects of holding negative perceptions of illness (Karademas, Kynigopoulou, Aghathangelou, & Anestis, 2011). This remains an under researched area and one which has yet to be explored in the context of a chronic degenerative disease.

PD is a chronic degenerative neurological disease which affects approximately 120,000 people in the UK (Parkinson's UK, 2007). It is characterised by progressive impairment of movement and balance with associated non-motor symptoms including cardio-vascular, gastrointestinal, mood, sleep, cognitive and sexual problems. PD presents significant challenges to patients and has a detrimental

impact on psychological well-being and quality of life (Schrag, Jahanshahi, & Quinn, 2000). Few studies have explored perceptions of PD and their relationship to outcome although preliminary studies have found associations between negative perceptions and depression and anxiety (Evans & Norman, 2009; Hurt et al., 2012). Given de Ridder et al.'s (2000) previous findings in PD and optimism this was selected as an appropriate patient group within which to explore both linear and non-linear relationships between illness perceptions and outcome.

The aims of the present study were fivefold: (i) to explore the linear associations between illness perceptions, optimism and outcome; (ii) to attempt to replicate de Ridder's finding of a non-linear relationship between optimism and well-being in PD; (iii) to conduct a detailed exploration of the nature of the relationships between specific illness perceptions and outcome and to determine whether a linear or non-linear relationship best described the data; (iv) to identify statistical predictor of well-being and (v), to test for a possible moderating effect of optimism on the relationship between illness perceptions and well-being.

Methods

Participants

Participants were recruited from a cohort of patients involved in a prospective study of mood states in Parkinson's disease (PROMS-PD) (Brown et al., 2011). This was a large representative prevalence sample with patients excluded from the study only if they had severe sensory loss (hearing or vision) or communication difficulties that would interfere with the assessment process or scored below 24 on the Mini-Mental State Examination (Folstein et al., 1975), indicative of the presence of a possible dementia syndrome. Participants either completed postal questionnaires or were visited at home by the researcher. Written consent was provided by all participants (Ethics ref: 08/H0808/65).

Measures

Illness Perceptions

The Illness Perception Questionnaire – Revised (IPQ-R) (Moss-Morris et al., 2002) is a questionnaire measure of illness perceptions designed for use in a range of physical and mental health conditions. The measure consists of nine subscales: identity (16 items), consequences (6 items), timeline acute/chronic (6 items), timeline cyclical (4 items), personal control (6 items), treatment control (5 items), emotional representation (6 items), illness coherence (understanding of illness) (5 items) and cause (18 items). All subscales are rated on a five point scale (agree-disagree) with the exception of identity which consists of a generic symptom list rated on a yes/no scale. The IPQ-R is commonly adapted for use in various health conditions. Throughout the wording was changed from ‘illness’ to ‘Parkinson’s’, for example ‘My illness strongly affects the way other people see me’ became ‘My Parkinson’s strongly affects the way other people see me’. Three PD specific symptoms were added to the symptom list (identity subscale), loss of strength, slowness of movement and tremor, to improve acceptability amongst a PD sample. All of the subscales demonstrated good reliability (table 1), with the exception of treatment control which was found to be unreliable with an alpha of .42 (Kline, 1999). Reliability of this subscale improved when the item ‘my treatment will be effective in curing my Parkinson’s’ was removed but reliability remained low (.51). The cause items were not included in the present analysis. The cause subscales proposed in the original IPQ-R paper have shown poor validity and reliability (Moss-Morris et al., 2002). No specific hypotheses were made regarding the cause items and an item by item analysis was considered to be beyond the scope of the present paper.

Optimism

The Revised Life Orientation Test (LOT-R) (Scheier, Carver, & Bridges, 1994) is a questionnaire measure of optimism and pessimism consisting of six items and four filler items. Participants rate statements on a five point (1-5) I agree a lot-I disagree a lot scale. Three items are negatively worded and three are positively worded. The negatively worded items were reverse scored and scores from

all six items were summed. In the present analyses higher scores indicate less optimism. The LOT-R demonstrated good internal consistency (table 1).

Psychological well-being

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) is a 14 item self-report measure of anxiety and depression. Participants rate items on a 4 point scale representing degree of distress: 0 = none, 1 = a little, 2 = a lot, 3 = unbearably. Subscale scores can be computed for depression and anxiety, scores of 8-10 indicate 'possible' depression or anxiety, and 11+ a 'definite' problem. The HADS has been validated for use in PD showing good internal consistency (0.88)(Marinus, Leentjens, Visser, Stiggelbout, & van Hilten, 2002; Mondolo et al., 2006). The total score gives an overall rating of psychological distress and showed good internal consistency in the present study (table 1).

Health Related Quality of Life

Health related quality of life (HRQoL) was assessed using the Parkinson's Disease Questionnaire (PDQ-8), developed and validated in patients with PD and commonly used in both research and clinical practice (Jenkinson & Fitzpatrick, 2007; Jenkinson, Fitzpatrick, Petrone, Greenhall, & Hyman, 1997; Tan, Lau, Au, & Luo, 2007). It generates a single index score ranging from 0 to 100 with a higher score indicating poorer HRQoL. The measured showed good internal consistency (table 1).

Disease Severity

The Unified Parkinson's Disease Rating Scale (UPDRS) (Fahn, Elton, & 1987) is a clinician rated measure of severity of PD motor symptoms. Higher scores indicate greater motor dysfunction. Hoehn and Yahr staging (Hoehn & Yahr, 1967) gives an overall rating of disease severity. Ratings of 1-2 indicate mild disease, and 3-5 indicate moderate to severe disease.

Cognition

The Addenbrooke's Cognitive Examination – Revised (ACE-R) (Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006) is a brief cognitive test that assesses five cognitive domains: attention/orientation, memory, fluency, language and visuo-spatial. Total scores range from 0-100, a higher score indicates better functioning. The ACE-R has demonstrated reliability in a PD population (Reyes et al., 2009).

Statistical Analysis

Statistical analyses were conducted using IBM SPSS 19.0. In order to explore whether a linear or curvilinear relationship best explained the associations between optimism and outcome (psychological well-being and HRQoL), and a subset of illness perceptions and outcome, a number of statistical tests were employed. Firstly simple correlations were performed between illness perceptions, optimism and outcome variables. Correlations were also assessed between demographic variables and clinical measures of disease severity including UPDRS, Hoehn and Yahr and cognition (ACE-R) with HRQoL and psychological well-being. Secondly, following the method used by de Ridder et al. (2000) squared optimism and illness perception variables were computed in order to model a curvilinear (quadratic) effect. The optimism and illness perception variables were mean-centred, squared and then inverted by multiplying by -1. These variables will be referred to as 'squared variables'. Simple correlations were used to explore the relationships between the squared variables, psychological well-being and HRQoL. Thirdly, both linear and curvilinear relationships between optimism, illness perceptions and outcome variables were estimated and the fit of both curves compared. In order to statistically compare the linear and quadratic models to determine the best fit the residual values were converted to absolute values and compared using paired samples t-tests. A superior model would be one with significantly smaller residual values. There are a variety of statistics by which the 'fit' of the quadratic and linear curves can be judged (F-statistics, adjusted R square, mean residuals). As we were principally interested in determining the nature of the relationship rather than trying to determine which of the models accounted for the most variance the mean residuals were selected as the statistic of relevance. Finally multiple regression analyses

were used to identify statistical predictors of psychological well-being and HRQoL. Only variables significantly associated with outcome in the univariate analyses were entered into the models ($p \leq 0.05$). Demographic and clinical variables significantly correlated with outcome were also included in the model allowing the relative importance of these variables to be assessed. Only those illness perception variables which logically could be 'unrealistically positive' were included in the analysis. For example believing that PD will have no consequences is unrealistically positive, PD will have consequences for all patients. However it is not logical to think of all dimensions in this way. For example holding strong illness coherence beliefs can be a realistic positive belief. It is perfectly reasonable for a patient to feel they have a clear understanding of PD, this would not be considered as unrealistically positive. The scales where unrealistically positive illness perceptions were conceptually possible were timeline acute/chronic, consequences, treatment control and personal control.

The hypothesised moderating effect of optimism on the relationship between illness perceptions and outcome was tested using multiple regression analyses. All illness perception variables and optimism were mean centred. A product term was then created by multiplying the predictor (illness perception variables) by the moderator (optimism). A series of hierarchical multiple regression models were run for each illness perception variable and each outcome variable (psychological well-being and HRQoL). In each model the predictor variable and the moderator were entered into the first step. The product term was entered into the second step of the model to test for moderation. Patients were stratified as low ($n=14$), medium ($n=69$) or high ($n=23$) optimism based on their LOT-R score. In accordance with previous authors e.g. de Ridder et al. (2000) and Karademas (2012) scores below 1 standard deviation and above 1 standard deviation from the mean were used to define groups.

Results

Descriptives

109 participants were recruited (55 female, 54 male). 47% of the sample left school aged 14-15 years and 53% aged 16-18 years. 30% attended higher education. The sample had a mean age of 68.0 years (range = 50-90, SD = 8.34), mean ACE-R score of 87.8 (range 54-100, SD = 8.69), and mean duration of PD of 8.1 years (range = 0-26, SD = 5.29). The UPDRS was used to assess severity of PD, mean UPDRS III score was 29.5 (range = 8-70, SD = 11.86) and mean Hoehn and Yahr score was 2.5 (range = 1-5, SD = .80). Total levodopa equivalent daily dose (LEDD – standardised measure of PD medication) was calculated using the Tomlinson et al. (2010) criteria, median daily dose was 675.0 (range = 0 – 7565, interquartile range = 722.50). The number of comorbidities in addition to PD was measured using the Older American Resources and Services Assessment (OARS, Fillenbaum, 1998). On average participants experienced 1.7 comorbidities (range 0-6, SD=1.5).

Table 1

Mean scores on the depression and anxiety measures fell within the ‘not depressed’ and ‘not anxious’ ranges. 27% scored in the ‘definitely anxious’ range and 15% scored in the ‘definitely depressed’ range. 24% of the sample were taking an anti-depressant, these participants had significantly higher total HADS scores (taking anti-depressant: mean 17.21, not taking anti-depressant: mean 12.81, $t_{(103)}=-2.843$, $p=0.005$). Standard illness perception and optimism scores are shown in table 1. The most strongly endorsed illness perceptions were timeline chronic and consequences, the least strongly endorsed were personal control and illness coherence.

Correlational analyses between illness perceptions, optimism, psychological well-being and quality of life

Table 2

Greater disease severity, longer disease duration and higher LEDD were associated with poorer HRQoL and psychological well-being. A range of raw illness perception and optimism scores were

strongly correlated with psychological well-being and HRQoL, with negative perceptions predicting poorer outcome (table 2). Holding a strong illness identity, perceiving a cyclical timeline and serious consequences, holding a negative emotional representation, having low illness coherence and low optimism all correlated with psychological distress and poor HRQoL. Additionally perceiving PD to have a chronic timeline and feelings of low personal control over PD were significantly associated with poor HRQoL.

Exploring non-linear relationships between illness perceptions, optimism, psychological well-being and quality of life

Correlations

Squared illness perception and optimism variables were correlated with HRQoL and psychological well-being (table 2). Only one of the squared variables indicated a significant curvilinear relationship: squared optimism significantly predicted psychological well-being.

Curve Estimation

Both linear and quadratic curves were estimated to model the relationships between the selected illness perceptions, optimism and psychological distress (table 3). All curves modelling illness perceptions and psychological distress were non-significant with the exception of consequences. Both the linear and quadratic curves were significant however there was no difference between the mean residuals indicating that neither curve was a superior fit of the data. Both the linear and quadratic curves also provided a significant model of the relationships between optimism and psychological distress. Although the mean residuals were not significantly different the quadratic curve had smaller mean residuals suggesting it describes the nature of the data more adequately than the linear model.

Significant relationships were seen between HRQoL and personal control, timeline acute chronic, consequences and optimism. Both the linear and quadratic curves provided a significant model. The mean residuals were smaller for quadratic curves than the linear curves suggesting that the quadratic curves provided a somewhat better explanation of the nature of the relationships but this was not statistically significant.

Table 3

Predictors of psychological well-being and quality of life

Illness perceptions were found to account for significant variance in psychological well-being and HRQoL (Table 4). Holding a strong illness identity, having a negative emotional reaction towards PD and lower optimism predicted poorer psychological well-being. Interestingly squared optimism still significantly predicted well-being after optimism in its linear form had been included in the model adding some support for an independent non-linear relationship between optimism and well-being. Visual inspection of the data suggests that while high optimism is not associated with worse well-being compared to medium levels, neither does it offer much in the way of advantage (figure 1). The low optimism group showed the highest mean HADS score (22.43, SD=7.41), followed by the medium group (13.78, SD=6.52) and the high optimism group (10.26, SD=5.11). A one-way Analysis of Variance found a significant difference in HADS scores between groups ($F_2=16.216$, $p<.001$). Hochberg's GT2 post hoc test indicated that the low optimism group had significantly higher HADS scores than the medium and high optimism group but no statistically significant difference was found between the medium and high optimism groups.

Figure 1

Poor HRQoL was predicted by strong illness identity, cyclical timeline, serious consequences and low illness coherence. Optimism was not a significant predictor of HRQoL (Table 4).

Moderating effect of optimism

Pearson's correlations were used to explore the relationships between illness perceptions and optimism (Table 5). Perceptions of serious consequences, low personal control and low illness coherence and negative emotional representation correlated with low optimism. The moderating effect of optimism on the relationship between illness perceptions and psychological well-being and HRQoL was examined in a series of multiple regression analyses. Sixteen analyses were performed in total, one regression for each of the eight illness perception dimensions predicting both outcome variables (HADS and HRQoL). Optimism was found to moderate the relationship between timeline acute/chronic and HRQoL ($p=.032$) (Figure 2) and illness coherence and psychological distress ($P=.036$) (Figure 3). Two borderline significant effects were identified between emotional representation and HRQoL ($p=.084$) and illness coherence and HRQoL ($p=.080$). In all models those participants in the lower optimism group had a poorer HRQoL or psychological well-being than those in the higher optimism group irrespective of their illness perceptions (figures 2 & 3). For the purposes of visual inspection of the data participants were divided into lower and higher optimism groups based on mean scores. Interestingly the interaction effect of optimism and illness coherence was most visible at medium levels of illness coherence.

Figures 2 and 3

Discussion

The illness perception literature indicates that holding positive perceptions of illness results in better patient outcomes (Evans & Norman, 2009; Hagger & Orbell, 2003). The findings of this study are consistent with that research, positive perceptions of PD predicted better HRQoL and psychological well-being with the exception of treatment control. Illness perceptions were shown to be better predictors of HRQoL and psychological well-being than clinical and demographic variables. No evidence was found to support the hypothesised inverted U-shaped relationships between illness

perceptions and well-being. It is however interesting to note that three of the four chosen illness perceptions failed to significantly predict psychological well-being in the univariate analyses and neither psychological well-being nor HRQoL in the multivariate analyses namely: timeline acute/chronic, personal control and treatment control. These perceptions are commonly associated with psychological well-being (Hagger & Orbell, 2003). This lack of correlation may be a reflection of the fact that perceiving PD to have an acute timeline and to be highly controllable is not realistic and consequently potentially not adaptive and therefore is not associated with good psychological well-being. The finding suggests that perceptions associated with better well-being may be condition specific, although similar conditions may show some commonalities in adaptive perceptions e.g. degenerative conditions. Overall, the findings add to the body of literature which suggests that helping patients to develop positive perceptions of their illness can lead to better mental and physical health outcomes.

One potential reason for the lack of curvilinear relationship between illness perceptions and HRQoL and psychological well-being may be because participants in this study did not actually display extremely positive perceptions of acute timeline, consequences and personal and treatment control. Had a greater range of beliefs been demonstrated by the sample a curvilinear relationship may have been found. This may be a feature of the sample recruited into the present study with the majority of patients having several years experience of the disease and therefore able to form realistic beliefs. Different processes may apply in patients early in the course of disease. In addition, excellent information is available on the nature of PD, its treatment and course that may counter potentially unrealistic beliefs and perceptions. Further research is needed to explore the role of time since diagnosis and disease knowledge. Until this time it may be premature to fully abandon the idea of curvilinear relationships between illness perceptions and well-being in PD.

Overall patients with higher levels of optimism showed better well-being than patients with low levels of optimism consistent with previous research (de Ridder et al., 2000; Shifren, 1996). Furthermore optimism was shown to be protective against the effects of a subset of negative illness perceptions, replicating findings in other health conditions (Karademas et al., 2011). These findings suggest that optimism may in fact be a more important therapeutic target than illness perceptions themselves. Interestingly the interaction between optimism and illness coherence was most evident at medium levels of coherence. This finding could indicate that optimism exerts a strong effect on mood when illness beliefs are weak, i.e. no strong perceptions of low or high illness coherence. Further research is needed to test this hypothesis.

There was some evidence for a non-linear relationship between optimism and psychological well-being. In line with previous findings (de Ridder et al., 2000) it appears that having marked optimism may not confer any additional benefit to well-being over moderate levels of optimism, although there was no evidence that such optimism was maladaptive. In the context of PD this finding may reflect the fact that difficulties caused by the illness will occur no matter how optimistic one is. The challenges presented by PD may negatively affect mood even in the presence of high optimism. However a strong linear relationship was also present between optimism and mood suggesting a need for further work to adequately explain the relationship between optimism and mood.

Cognitive behavioural interventions designed to improve psychological well-being are increasingly popular in PD (Dobkin et al., 2011). These interventions often involve components of 'cognitive restructuring' a method of helping patients to restructure unhelpful thoughts about their PD and develop a more adaptive and usually positive view of their illness. Intervention studies in other health conditions have attempted to improve patient well-being and functioning through the adoption of positive illness perceptions e.g. Broadbent, Ellis, Thomas, Gamble, and Petrie (2009). While our findings suggest that targeting negative perceptions of PD may bring about better

psychological well-being and HRQoL fostering an optimistic attitude may be just as beneficial, if not more so.

Few intervention studies have been conducted specifically targeting optimism. However a small number of studies have provided evidence that using Cognitive Therapy to challenge negative thinking styles can bring about increases in optimism (Derubeis et al., 1990, Hoffart et al., 2002). More recently a psychological intervention utilising 'meaning-making' coping strategies lead to increased optimism in patients undergoing treatment for cancer (Lee et al., 2006). The intervention involved an exploration of the meaning of emotional responses to illness with reference to future hopes and past events. As an intervention which aims to understand the impact of illness on the patient's life and increase adjustment to illness, 'meaning-making' coping could potentially be effective in increasing optimism in patients with PD.

The most effective therapy may focus on changing specific illness beliefs but also helping patients to develop a more optimistic attitude in general. Those patients with very negative perceptions of illness and a very pessimistic attitude should specifically be targeted as these patients are most at risk of poor psychological well-being and HRQoL. The findings also indicate which specific illness perceptions would be beneficial targets for therapy. Contrary to previous illness perception studies the findings suggest there may be little benefit for PD patients in attempting to challenge perceptions of PD as uncontrollable. This is consistent with previous research into control perceptions in PD which suggested that attempting to increase perceptions of personal control of PD may actually be maladaptive, leading to expectations of decreased need for expert support (Eccles et al., 2011). However, challenging perceptions concerning the consequences of PD and improving understanding of PD may lead to improved outcomes. The present results would not support the specific targeting of potentially over-enthusiastic views or unrealistic positive health beliefs.

The present study was limited by the available sample size which was relatively small, had a larger sample been available the observed moderating effect of optimism on illness perceptions and

outcome may have been stronger. The low reliability of the treatment control scale suggests that treatment perceptions may not have been adequately assessed. Consequently the non-significant relationship between treatment control and outcomes must be viewed with some caution. The poor reliability of the treatment control scale may be related to the nature of PD. Treatment can be effective at controlling symptoms in the short term. Once medication wears off disabling symptoms start to reappear. Consequently a patient may view their illness as amenable to control but not amenable to improvement. Furthermore, all data was cross sectional preventing any statements about the direction of causality in the relationship between illness perceptions, optimism and outcome.

The findings have significant implications for clinical practice and therapeutic interventions not only for patients with PD but also other chronic degenerative diseases. Optimism has been shown to provide protection against some negative perceptions of illness and therefore therapy should aim to help patients foster an optimistic attitude. However it seems that having very marked optimism may not confer any additional benefit above moderate levels of optimism. It is recommended that therapy aims to help patients with pessimism and hopelessness develop positive perceptions of illness to maximise adaptation and psychological well-being. Further longitudinal investigations of optimism, illness perceptions and outcome in both PD and other chronic diseases are required to fully understand the nature of these relationships.

References

- Broadbent, E., Ellis, C. J., Thomas, J., Gamble, G., & Petrie, K. J. (2009). Further development of an illness perception intervention for myocardial infarction patients: a randomized controlled trial. *Journal of Psychosomatic Research, 67*(1), 17-23. doi: 10.1016/j.jpsychores.2008.12.001
- Brown, R. G., Landau, S., Hindle, J. V., Playfer, J., Samuel, M., Wilson, K. C., . . . Burn, D. J. (2011). Depression and anxiety related subtypes in Parkinson's disease. *Journal of Neurology Neurosurgery and Psychiatry, 82*(7), 803-809. doi: 10.1136/jnnp.2010.213652
- DeRubeis, R.J., Evans, M.D., Hollon, S.D., Garvey, M.J., Grove, W.M., & Tuason, V.B. (1990). How does cognitive therapy work? Cognitive change and symptom change in cognitive therapy and pharmacotherapy for depression. *Journal of Consulting & Clinical Psychology, 58*, 862–869.
- de Ridder, Denise, Schreurs, Karlein, & Bensing, Jozien. (2000). The relative benefits of being optimistic: Optimism as a coping resource in multiple sclerosis and Parkinson's disease. *British Journal of Health Psychology, 5*(2), 141-155. doi: 10.1348/135910700168829
- Dobkin, R. D., Menza, M., Allen, L. A., Gara, M. A., Mark, M. H., Tiu, J., . . . Friedman, J. (2011). Cognitive-behavioral therapy for depression in Parkinson's disease: a randomized, controlled trial. *American Journal of Psychiatry, 168*(10), 1066-1074. doi: 10.1176/appi.ajp.2011.10111669
- Eccles, F.R.J., Murray, C., & Simpson, J. (2011). Perceptions of cause and control in people with Parkinson's disease. *Disability and Rehabilitation, 33*(15-16), 1409-1420.
- Evans, D., & Norman, P. (2009). Illness representations, coping and psychological adjustment to Parkinson's disease. *Psychology and Health, 24*(10), 1181-1196. doi: 10.1080/08870440802398188
- Fahn, S. & Elton, R.L. (1987). Unified Parkinson's Disease Rating Scale. In S. Fahn, C.D. Marsden & D. Calne (Eds.), *Recent Development in Parkinson's Disease* (Vol. 2, pp. 153-163). Florham Park, NJ MacMillan Healthcare.

- Fillenbaum, G.G. (1998) *Multidimensional Functional Assessment of Older Adults: The Duke Older Adult Resources and Services Procedures*. Lawrence Erlbaum Associates. Hillsdale: NJ.
- Groarke, A., Curtis, R., Coughlan, R., & Gsel, A. (2004). The role of perceived and actual disease status in adjustment to rheumatoid arthritis. *Rheumatology*, *43*(9), 1142-1149. doi: 10.1093/rheumatology/keh262
- Gustavsson-Lilius, M., Julkunen, J., Keskivaara, P., Lipsanen, J., & Hietanen, P. (2012). Predictors of distress in cancer patients and their partners: the role of optimism in the sense of coherence construct. *Psychology and Health*, *27*(2), 178-195. doi: 10.1080/08870446.2010.484064
- Hagger, Martin S., & Orbell, Sheina. (2003). A Meta-Analytic Review of the Common-Sense Model of Illness Representations. *Psychology & Health*, *18*(2), 141-184. doi: 10.1080/088704403100081321
- Hoehn, M. M., & Yahr, M. D. (1967). Parkinsonism: onset, progression and mortality. *Neurology*, *17*(5), 427-442.
- Hoffart, A. & Sexton, H. (2002) The role of optimism in the process of schema-focused cognitive therapy of personality problems. *Behaviour Research and Therapy*, *40*(6), 611-623.
- Hurt, C. S., Weinman, J., Lee, R., & Brown, R. G. (2012). The Relationship of Depression and Disease Stage to Patient Perceptions of Parkinson's Disease. *Journal of Health Psychology*. doi: 10.1177/1359105311428537
- Jenkinson, C., & Fitzpatrick, R. (2007). Cross-cultural evaluation of the short form 8-item Parkinson's Disease Questionnaire (PDQ-8): results from America, Canada, Japan, Italy and Spain. *Parkinsonism and Related Disorders*, *13*(1), 22-28. doi: S1353-8020(06)00146-5 [pii]10.1016/j.parkreldis.2006.06.006
- Jenkinson, C., Fitzpatrick, R., Petrone, A., Greenhall, R., & Hyman, N. (1997). The PDQ-8: development and validation of a short-form Parkinson's disease questionnaire. *Psychology & Health*, *12*, 805-814.

- Jopson, N. M., & Moss-Morris, R. (2003). The role of illness severity and illness representations in adjusting to multiple sclerosis. *Journal of Psychosomatic Research*, 54(6), 503-511.
- Kaptein, A. A., Hughes, B. M., Scharloo, M., Fischer, M. J., Snoei, L., Weinman, J., & Rabe, K. F. (2008). Illness perceptions about asthma are determinants of outcome. *Journal of Asthma*, 45(6), 459-464. doi: 10.1080/02770900802040043
- Karademas, E. C. (2012). Conditional indirect relations of cardiac patients' subjective health to optimism through illness representations: a self-regulation circuit. *Journal of Health Psychology*, 17(1), 36-45. doi: 10.1177/1359105311405554
- Karademas, E. C., Kynigopoulou, E., Aghathangelou, E., & Anestis, D. (2011). The relation of illness representations to the 'end-stage' appraisal of outcomes through health status, and the moderating role of optimism. *Psychology & Health*, 26(5), 567-583. doi: 10.1080/08870441003653488
- Kline, P. (1999). *The handbook of psychological testing* (2nd ed.). London: Routledge.
- Lee, V., Cohen, S.R., Edgar, L. , Laizner, A.M., Gagnon, A.J. (2006) Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy. *Social Science and Medicine*, 62(12), 3133-3145.
- Leventhal, H, Nerenz, D, & Steele, C. (1984). Illness representations and coping with health threats. In A. Baum & J. Singer (Eds.), *A Handbook of Psychology and Health* (pp. 219-252). Hillsdale, NJ: Erlbaum.
- Leventhal, H., Brissette, I., & Leventhal, E. (2003) The common-sense model of self-regulation of health and illness. In L.D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour*. (pp. 42-65). London: Routledge.
- Marinus, J., Leentjens, A. F., Visser, M., Stiggelbout, A. M., & van Hilten, J. J. (2002). Evaluation of the hospital anxiety and depression scale in patients with Parkinson's disease. *Clinical Neuropharmacology*, 25(6), 318-324 .

- Mioshi, E., Dawson, K., Mitchell, J., Arnold, R., & Hodges, J. R. (2006). The Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry, 21*(11), 1078-1085. doi: 10.1002/gps.1610
- Mondolo, F., Jahanshahi, M., Grana, A., Biasutti, E., Cacciatori, E., & Di Benedetto, P. (2006). The validity of the hospital anxiety and depression scale and the geriatric depression scale in Parkinson's disease. *Behav Neurol, 17*(2), 109-115.
- Moss-Morris, Rona, Weinman, John, Petrie, Keith, Horne, Robert, Cameron, Linda, & Buick, Deanna. (2002). The Revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health, 17*(1), 1-16. doi: 10.1080/08870440290001494
- Parkinson's UK. (2007). A Professional's Guide to Parkinson's Disease, from http://www.parkinsons.org.uk/pdf/B126_Professionalsguide.pdf.
- Petrie, K. J., Jago, L. A., & Devcich, D. A. (2007). The role of illness perceptions in patients with medical conditions. *Current Opinion in Psychiatry, 20*(2), 163-167. doi: 10.1097/YCO.0b013e328014a871
- Reyes, M. A., Lloret, S. P., Gerscovich, E. R., Martin, M. E., Leiguarda, R., & Merello, M. (2009). Addenbrooke's Cognitive Examination validation in Parkinson's disease. *European Journal of Neurology, 16*(1), 142-147. doi: ENE2384 [pii] 10.1111/j.1468-1331.2008.02384.x
- Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. *Journal of Personality & Social Psychology, 67*(6), 1063-1078.
- Schrag, A., Jahanshahi, M., & Quinn, N. (2000). How does Parkinson's disease affect quality of life? A comparison with quality of life in the general population. *Movement Disorders, 15*(6), 1112-1118.
- Shifren, K. (1996). Individual differences in the perception of optimism and disease severity: a study among individuals with Parkinson's disease. *Journal Behavioural Medicine, 19*(3), 241-271.

- Tan, L. C., Lau, P. N., Au, W. L., & Luo, N. (2007). Validation of PDQ-8 as an independent instrument in English and Chinese. *Journal of Neurological Science*, 255(1-2), 77-80. doi: S0022-510X(07)00101-3 [pii]10.1016/j.jns.2007.01.072
- Tomlinson, C. L., Stowe, R., Patel, S., Rick, C., Gray, R., & Clarke, C. E. (2010). Systematic review of levodopa dose equivalency reporting in Parkinson's disease. *Movement Disorders*, 25(15), 2649-2653. doi: 10.1002/mds.23429
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370.

Table 1 Descriptive Statistics: Illness perceptions, Optimism, and Outcome variables

	Range	Mean	Std. Deviation	Reliability (Cronbach's alpha)
HADS Anxiety Score	0-18	7.50	4.18	.84
HADS Depression Score	0-18	6.60	3.90	.81
Total HADS Score	0-32	12.12	7.18	.88
Identity	1.00-16	7.72	3.07	†
Timeline acute/chronic	2.67-5	4.47	.53	.80
Timeline cyclical	1.00-5	3.03	.93	.83
Consequences	1.83-5	3.78	.65	.73
Personal control	1.00-4.67	2.92	.79	.80
Treatment control	1.20-4.2	3.12	.50	.42
Illness coherence	1.00-5	2.97	.84	.85
Emotional representation	1.17-5	3.14	.81	.83
LOT-R Score	6.00-30	16.13	5.13	.74
PDQ-8 Scale Score	.00-84.38	35.18	17.83	.77

HADS = Hospital Anxiety and Depression Score, LOT-R = Life Orientation Test – Revised, PDQ-8 = Parkinson's Disease Questionnaire – 8

† Reliability was not calculated for the identity scale as this is a yes/no symptom list

Table 2. Simple correlations of clinical and demographic variables, illness perceptions, and optimism with outcome variables

	HADS	PDQ-8
	<i>r</i> (p)	<i>r</i> (p)
<i>Clinical and demographic variables</i>		
Sex	.027 (.780)	-.029 (.769)
Age	-.044 (.649)	-.177 (.072)
ACE-R Score	-.122 (.214)	.007 (.941)
UPDRS Score	.167 (.084)	.302** (.002)
Duration of PD	.189* (.050)	.217* (.027)
Total LEDD†	.199* (.039)	.255** (.009)
H&Y	.171 (.077)	.274** (.005)
Number of comorbid conditions	-.067 (.492)	.123 (.212)
<i>Raw illness perception and optimism variables</i>		
Identity	.424** (<.001)	.492** (<.001)
Timeline acute/chronic	.161 (.098)	.248* (.011)
Timeline cyclical	.226* (.019)	.406** (<.001)
Consequences	.415** (<.001)	.586** (<.001)
Personal control	-.173 (.074)	-.292** (.003)
Treatment control	-.168 (.084)	-.174 (.077)
Illness coherence	-.249** (.010)	-.211* (.032)
Emotional representation	.549** (<.001)	.451** (<.001)
LOT-R	.559** (<.001)	.406** (<.001)
<i>Squared illness perception and optimism variables</i>		

Timeline acute/chronic sq	.169 (.082)	.085 (.393)
Consequences sq	.096 (.326)	.095 (.338)
Personal control sq	-.107 (.272)	-.171 (.083)
Treatment control sq	-.076 (.436)	-.063 (.522)
LOT-R sq	-.224* (.021)	-.177 (.073)

HADS = Hospital Anxiety and Depression Score, LOT-R = Life Orientation Test – Revised, PDQ-8 = Parkinson’s Disease Questionnaire – 8,

ACE-R= Addenbrooke’s Cognitive Examination – Revised, UPDRS= Unified Parkinson’s Disease Rating Scale, LEDD= Levodopa Equivalent

Daily Dose, H&Y= Hoehn and Yahr Staging

*Significant at p<.05, ** Significant at p<.01, sq=squared variable.

Table 3. Linear and Quadratic Curve Estimation

	Adjusted R Squared	F statistic	Significance	Mean Residuals	Paired samples T-test (T)	P
<i>Psychological well-being (HADS)</i>						
Timeline acute-chronic (L)	.017	2.79	.098	5.71		
Timeline acute-chronic (Q)	.016	1.87	.160	5.70	.513	.609
Personal control (L)	.021	3.25	.074	5.75		
Personal control (Q)	.016	1.87	.164	5.74	.263	.793
LOT-R (L)	.306	47.39**	<.001	5.00		
LOT-R (Q)	.328	26.60**	<.001	4.85	1.178	.241
Consequences (L)	.164	21.82**	<.001	5.27		
Consequences (Q)	.159	11.01**	<.001	5.27	.111	.912
Treatment control (L)	.019	3.05	.084	5.68		
Treatment control (Q)	.010	1.53	.221	5.69	-.686	.494
<i>HRQoL (PDQ-8)</i>						
Personal control (L)	.077	9.54**	.003	14.14		
Personal control (Q)	.075	5.20**	.007	14.09	.337	.736
Timeline acute-chronic (L)	.052	6.66*	.011	14.02		
Timeline acute-chronic (Q)	.048	3.59*	.031	13.96	.579	.564
Treatment control (L)	.021	3.19	.077	14.54		
Treatment control (Q)	.011	1.58	.211	14.54	-.265	.792
LOT-R (L)	.157	19.95**	<.001	13.45		
LOT-R (Q)	.166	11.18**	<.001	13.33	.537	.592

Consequences (L)	.337	53.37**	<.001	11.31		
Consequences (Q)	.342	27.78**	<.001	11.16	.798	.426

L = Linear Curve, Q = Quadratic curve, LOT-R = Life Orientation Test – Revised, *Significant at $p < .05$, ** Significant at $p < .01$

Table 4. Multiple regression models showing regression coefficients, confidence intervals and p values of predictors of psychological well-being and health related quality of life

	Unstandardised		Standardised		95.0% Confidence	
	coefficients		coefficients		Interval for B	
	Beta	Std Error	Beta	P Value	Lower Bound	Upper Bound
<i>Psychological well-being (HADS)</i>						
PD Duration	.073	.699	.053	.462	-.123	.270
LEDD	.000	.001	.036	.612	-.001	.001
Identity	.540	.177	.228**	.003	.118	.893
Timeline cyclical	.281	.577	.035	.627	-.865	1.427
Consequences	.975	.856	.088	.257	-.723	2.674
Illness coherence	-1.036	.622	-.118	.099	-2.269	.198
Emotional representation	2.889	.715	.314**	<.001	1.469	4.309
LOT-R	.451	.111	.320**	<.001	.231	.672
LOT-R sq	-.029	.013	-.154*	.026	-.054	-.004
<i>HRQoL (PDQ-8)</i>						
UPDRS Score	.143	.113	.097	.210	-.082	.367
Duration of PD	-.060	.251	-.018	.811	-.559	.439
Hoehn & Yahr Score	3.196	1.830	.144	.084	-.440	6.832
LEDD	-.001	.001	-.029	.671	-.003	.002
Identity	1.205	.431	.206**	.006	.349	2.061
Timeline cyclical	4.603	1.498	.237**	.002	1.745	7.460
Consequences	9.912	2.293	.354**	.000	5.357	14.467

Emotional representation	3.049	1.767	.133	.088	-.462	6.560
Personal control	-.443	1.649	-.019	.789	-3.719	2.834
Illness coherence	-3.926	1.498	-.182*	.010	-6.903	-.950
Timeline acute/chronic	4.023	2.443	.120	.103	-.830	8.875
LOT-R	.296	.280	.085	.294	-.261	.853

HADS = Hospital Anxiety and Depression Score, LOT-R = Life Orientation Test – Revised, PDQ-8 = Parkinson’s Disease Questionnaire – 8,

UPDRS= Unified Parkinson’s Disease Rating Scale, LEDD= Levodopa Equivalent Daily Dose, H&Y= Hoehn and Yahr Staging

HADS: Adjusted R Squared = .540, f = 14.68 p <.001, PDQ-8: Adjusted R Squared = .585, f = 13.00 p <.001

Table 5. Pearson's correlations between illness perceptions and optimism

Illness perception variables	Pearson's <i>r</i>
Identity	.158
Timeline acute/chronic	.007
Timeline cyclical	.097
Consequences	.344**
Personal control	-.323**
Treatment control	-.072
Illness coherence	-.321**
Emotional representation	.354**

Figure 1. Plot of psychological well-being against level of optimism

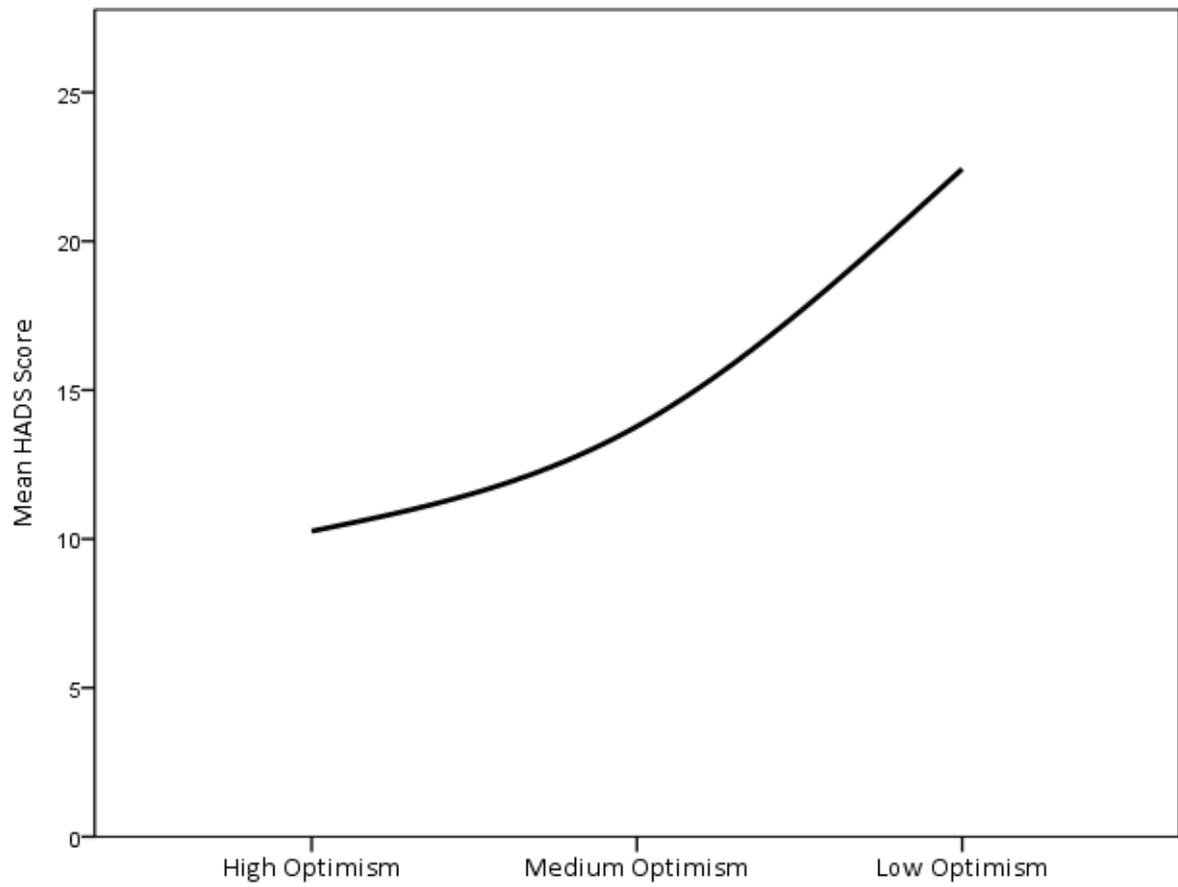


Figure 2. Plot of Timeline acute/chronic scores against health related quality of life by level of optimism

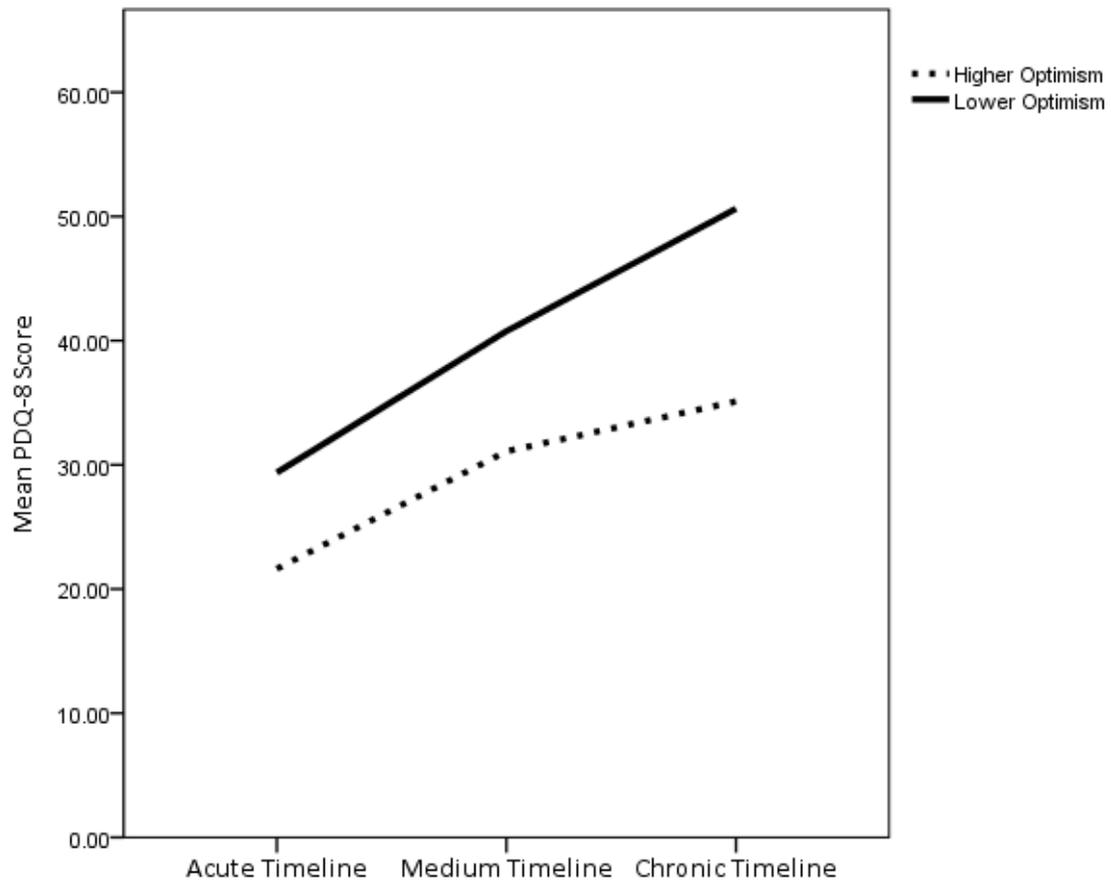


Figure 3. Plot of illness coherence scores against psychological well-being by level of optimism

