Trajectories of Illness Perceptions in Persons with Chronic Illness:

An Explorative Longitudinal Study

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Abstract

Accurate illness perceptions are essential to the self-management of chronic illness. This study explored trajectories of illness perceptions in persons with morbid obesity ($n = 53$) and persons with chronic obstructive pulmonary disease (COPD; $n = 52$) following a patient education course. Participants completed the *Brief Illness Perception Questionnaire* five times over a one-year period. Repeated measures analysis of variance was employed. Over time, obese participants perceived shorter illness duration, fewer consequences, less emotional stress, and more personal control. COPD participants had initial increases in personal control and understanding, but these changes were not maintained throughout the follow-up period.

Keywords: illness perception, morbid obesity, chronic obstructive pulmonary disease, longitudinal study.

The number of persons living with chronic illness in the Western world has increased over the years, much due to improvements in medical treatments (World Health Organization, 2008). Persons with chronic illness need to cope with symptoms and distress in order to maintain quality of life despite their illness. As suggested by the Common-Sense Model (CSM), accurate perceptions of illness form the cognitive basis for the person's adaptive coping responses (Cameron and Leventhal 2003; Petrie and Weinman, 1997). Perceptions of illness are therefore related to, yet separate from, the strategies the person can use for coping with illness (Cameron and Leventhal, 2003; Leventhal et al, 1980). Coping responses, in turn, are evaluated by the person in terms of their perceived effect on the health threat. The CSM, thus, depicts a self-regulatory system: Appraisals of coping influence the choice of future coping responses, leading to the abandonment of ineffective strategies and the continuation and refinement of effective ones. However, coping appraisals may also influence the way the illness is perceived and understood. Related to chronic illnesses, unsuccessful coping may result in perceiving the illness as uncontrollable, long-lasting and laden with negative consequences. A meta-analysis showed that perceiving the illness as more severe and with more consequences was related to worse health outcomes than perceiving it more positively (Hagger and Orbell, 2003).Thus, there is good reason to examine illness perceptions in persons with chronic illness.

Illness perceptions do not originate solely from personal experience. Sociocultural norms and attitudes are influential, e.g. patients and their family members often share similar views of the illness (Weinman et al, 2000). Health professionals also contribute to the person's illness perceptions, as in cases where a medical diagnosis is explained. However, all this information is processed through the patient's own selective mind. The resulting illness perceptions have been connected to five overarching domains (Cameron and Leventhal, 2003). *Identity* refers to the symptoms the person experiences, and the label under which the

symptoms can be subsumed. *Consequences* refer to the perceived impact of illness on the person's life. *Cause*, on the other hand, is the state or act that is believed to have led to the onset of illness. *Controllability* concerns the extent to which the person believes that the illness can be cured or modified, either by self-management or by treatment. Finally, *timeline* is the perceived duration of illness.

For a variety of chronic illnesses, research has shown associations between illness perceptions and desirable outcomes: quality of life and well-being (Braido et al, 2011; Glattacker et al, 2013; Rochelle and Fidler, 2012; Scharloo et al, 2007); social functioning, emotional adjustment, and perceived health (Chilcot et al, 2011; Jopson and Moss-Morris, 2003; Scharloo et al, 2000); self-management and health promoting behaviors (Conner and Norman, 1996; Disler et al, 2012; Kaptein et al, 2008; Nouwen et al, 2009); treatment attendance and adherence (Fischer et al, 2009; Horne, 1997; Hsiao et al, 2012; Senior et al. 2005); and self-efficacy beliefs (Bonsaksen et al, 2012; Lau-Walker, 2004). In a study of patients with Parkinson's disease, illness perceptions differed between depressed and non-depressed participants, and also according to disease stage (Hurt et al, 2012). Moreover, associations between illness perceptions and outcome have been dependent on factors like phases of treatment (Lau-Walker, 2006) and self-perceived health status (Karademas, 2012). These studies underscore the importance, as well as the complex dynamics, of illness perceptions for individuals' health, well-being, and coping resources, and indicate that modifying them can be one relevant aspect of educational interventions.

Research indicates that illness perceptions can change over time (Astin and Jones, 2006; Bijsterbosch et al, 2009; Broadbent et al, 2009; Petrie et al, 2002; Petrie et al, 2012). Living with chronic illness can gradually change one's perception of related consequences, emotional responses, and control. Interventions, such as health education courses, can foster insights that lead persons to change their causal attributions (e.g., genes versus unhealthy

lifestyle) and subsequent behavior. Furthermore, one may expect different trajectories of illness perceptions over time for persons with different illnesses. For example, persons with chronic obstructive pulmonary disease (COPD) may expect their illness to continue for as long as they live, as COPD is considered a progressive disease with no cure. Persons with morbid obesity, on the other hand, may improve from their illness by changing lifestyle (exercise, diet) or by receiving treatment that can lead to an altered view of illness duration. However, both COPD and morbid obesity may alternatively be viewed as consequences of being addicted to smoking and eating, respectively. A perspective emphasizing similarities in this respect may lead to the opposite expectation of relatively equal illness perception trajectories over time.

So far, only one study has explored long-term trajectories of illness perceptions among persons with chronic illness (Kaptein et al, 2010). That study, however, was concerned exclusively with osteoarthritis patients. Our literature review did not reveal studies examining illness perception trajectories among the growing number of adults with obesity or COPD, neither studies comparing trajectories of groups with distinctly different illness characteristics.

Purpose

This study is part of a prospective longitudinal cohort study designed to evaluate 12 instruments assessing illness perceptions and coping strategies with regard to their ability to detect change over time and to explore changes in health-related quality of life among persons participating in patient education courses in Norway (Lerdal et al, 2011). The purpose of the present study was to explore the one-year trajectories of illness perceptions in persons with morbid obesity and in persons with COPD following their participation in a patient education course.

Research questions

1. How do illness perceptions change in persons with morbid obesity and persons with COPD during the first year following a patient education course?

2. How do illness perception trajectories differ for persons with morbid obesity compared to persons with COPD?

Method

Sample and data collection

Participants were recruited during 2009-2010 among persons with morbid obesity or COPD about to begin a patient education course. All participants were referred to the course by a physician. Course attendants were given verbal and written information about the study and were invited to participate. Of a total number of 312 course attendants, 242 (78 %) consented to participate. Participants completed the first set of questionnaires in a secluded room on-site and returned it in a sealed envelope. For the following assessments, participants completed the forms at home and returned them to the researchers by mail.

For this study, we used data from five assessment points: pre-course, post-course, and three, six, and 12 months after course completion. We excluded 137 participants (dropouts) because they did not have valid scores on all variables at every assessment, leaving a total sample of 105 participants for this study. Dropout was higher in the obesity group ($n =89$, 65.0 %) than in the COPD group ($n = 48$, 35.0 %, $p = 0.023$). In the sample, 53 participants (50.5 %) were diagnosed with morbid obesity; i.e., having a body mass index of 40 kg/m^2 or greater (World Health Organization, 2010). The remaining 52 participants (49.5 %) were diagnosed with COPD within GOLD stages 2 or 3, indicating moderate to severe limitation of airflow, respectively (Global Initiative for Chronic Obstructive Lung Disease, 2011). No sex differences were found between participants and dropouts in this study ($p = 0.84$), but participants ($M = 55.1$ years, $SD = 14.1$ years) were older than the dropouts ($M = 48.9$ years, $SD = 14.8$ years, $p = 0.001$, $d = 0.42$. COPD participants had lower scores on *emotional*

response (M = 4.6, SD = 2.6,) than the dropouts in this group (M = 5.8, SD = 3.1, p = 0.04, d = 0.42). For the obesity group, no differences between participants and dropouts were detected.

Patient education courses

The courses for both illness groups were designed to help participants achieve a realistic understanding of their illness, better self-management skills, and improved health-related quality of life (Lerdal et al, 2011). The approach was grounded in cognitive behavior theory and emphasized the participants' work in uncovering hidden resources, strengthening self-concept and social skills, and raising consciousness of lifestyle choices. The courses included subjects like available treatments and their consequences, lifestyle changes, and subsequent changes in mind and body. The course participants were encouraged to participate in subsequent self-help groups. The course for the obesity patients lasted nine weeks and consisted of 40 hours of education, including small group discussion and work with individualized action plans. The COPD courses lasted three to five weeks and included between 20 and 48 hours of education.

Measures

All measures were translated into Norwegian and validated before they were used in this study.

Illness perception

The *Brief Illness Perception Questionnaire* (BIPQ) (Broadbent et al, 2006) assesses representations of illness in eight single-item domains. Five cognitive domains assess: the impact of illness on the person's life (*consequences*), expected illness duration (*timeline*); feelings of control over the illness (*personal control*), belief in treatment effectiveness (*treatment control*); and the extent and severity of symptoms (*identity*). Two domains assess emotional representations of illness: *concern* and *emotional response*. One final domain assesses the person's *understanding* of the illness. The scores range between 0 and 10, with

higher scores indicating more of the measured construct. The instrument is a shorter version

of a previously revised instrument (IPQ-R; Moss-Morris et al, 2002) and is reported to have

good psychometric properties, in terms of test-retest reliability and concurrent, predictive, and

discriminant validity (Broadbent et al, 2006).

Sociodemographic background

Data for age, sex, formal education, employment status, and social support were

collected. Formal education was treated as a categorical variable: 12 years of education

(secondary education) or less *versus* more than 12 years education (university/college

education). Social support was rated on a five-point Likert-type scale, where higher scores

indicated more support.

Statistical analyses

Differences between the two illness groups at baseline were assessed by Chi-square

(χ^2) test for categorical variables or by *t*-test for continuous variables. Repeated measures

analyses of variance (ANOVA) were used to assess the trajectories of each of the eight illness

perception domains in the sample. In cases of significant interactions between time and

diagnostic group, the analysis was run separately for each group. In the two-way ANOVA, the

models controlled for participants' age and sex. Employment status was excluded as a

covariate because of the bivariate relationship between employment status and age ($r = 0.47$,

$p < 0.001$). For each time point, illness perception scores were analyzed for group differences

using a linear regression model controlling for age and sex, as in the two-way ANOVA.

Effect sizes (*ES*) were provided as Cohen's *d* and as partial η^2. Cohen's $d > 0.40$ and

partial $\eta^2 > 0.06$ were considered moderate effect sizes and clinically significant (Cohen,

1992). Adjustments for multiple comparisons were made by using the Bonferroni correction.

The level of significance was set at $p < 0.05$ and all tests were two-tailed. Data were analyzed

using SPSS for Windows v. 19 (SPSS Inc., 2010).

Ethics

The Norwegian Research Ethics Committee (REK S-08662c 2008/17575) and the Ombudsman of Oslo University Hospital approved of the study. Informed written consent was received from all participants.

Results

Sample characteristics and illness perceptions

The sample is described in Table 1. Differences between participants in the two groups were found on several sociodemographic variables at baseline. COPD participants were older, more likely to be male, and less likely to be in paid employment than obese participants. In addition, COPD participants perceived fewer *consequences*, more *personal control*, fewer symptoms (*identity*)*;* less *concern*, and less *emotional response* than the obese. Obese participants perceived a shorter *timeline* and more *treatment control* than COPD participants.

[Insert Table 1 about here]

Trajectories of illness perceptions

The trajectories of the illness perception domains for both groups are shown in Figure 1. Most trajectories were different between the groups, and remained so after controlling for age and sex, excepting the trajectories of *timeline, treatment control*, and *understanding*. Over time, the obese participants perceived their illness as less threatening (decreased *consequences* and *identity*) and themselves as gaining more *personal control*. In contrast, COPD participants generally showed either no change in illness perception or initial changes that were not maintained over time.

[Insert Figure 1 about here]

For perceived *consequences,* obese participants had a mainly linear decrease across time (F [1] = 67.8, $p < 0.001$, partial $\eta^2 = 0.57$), while the COPD group demonstrated no change in this regard. For *timeline*, the largest effect size was for a linear decrease among the

obese participants (F [1] = 22.4, p < 0.001, partial η^2 = 0.30), whereas COPD participants

showed no change across time. There was a linear increase in *personal control* across time for

the obesity group (F [1] = 26.0, p < 0.001, partial η^2 = 0.33), while the COPD group showed a

low-high-low change pattern (F [1] = 11.3, p = 0.001, partial η^2 = 0.18). For all participants,

treatment control decreased linearly (F [1] = 10.4, p = 0.002, partial η^2 = 0.09). There was a

linear decrease in symptoms (*identity*) among obese participants (F [1] = 50.5, p < 0.001,

partial η^2 = 0.49), whereas COPD participants showed no change across time. The obese

participants showed linearly decreasing *concern* (F [1] = 98.8, p < 0.001, partial η^2 = 0.66)

and a similar change pattern for *emotional response* (F [1] = 39.8, p < 0.001, partial η^2 =

0.43), while COPD participants showed no change over time on either of these illness

perceptions. For *understanding*, there was no change in the obese participants, whereas COPD

participants had the largest effect size for a low-high-low change pattern (F [1] = 18.0, p <

0.001, partial η^2 = 0.26).

Discussion

This study demonstrated that the obese participants showed favorable trajectories

across time, with scores indicating perceptions of fewer illness *consequences*, shorter

timeline, increased *personal control*, fewer symptoms (*identity*), less *concern*, and less

emotional response during the first year following a patient education course. These

trajectories were all clinically significant and showed statistically significant differences

compared to the COPD participants' trajectories. Among COPD participants, initial increases

in *personal control* and *understanding* were not maintained throughout the follow-up period.

According to the CSM, the patient education courses would represent one external

influence for the participant in the process of forming his or her perceptions about the illness

(Cameron and Leventhal, 2003). One purpose of the patient education courses was to provide

the participants with an accurate *understanding* of their illness, but also to initially help them

utilize it in their process of adapting towards a healthier lifestyle. Over time, changes in lifestyle (coping) and the positive appraisal of these changes may have the potential to modify illness perceptions.

Obese participants had no change in *understanding* across time. Given their consistently high scores in this domain, these participants may have felt that they already had adequate knowledge about their illness, including its causes and management, even before the patient education course started. The challenge for self-management may not be a lack of understanding, but rather the ability to initiate and maintain changes in lifestyle that follows from this understanding (Bonsaksen et al, 2011). Increasing motivation, self-efficacy, and healthy lifestyle habits may therefore be important aims of patient education courses for obese participants.

A study on patients with heart attack reported improved *understanding* up to six months after the intervention (Broadbent et al, 2009). In our study, participants in both groups had relatively high scores on *understanding* at one-year follow-up, suggesting that participants generally felt they understood their illness. However, the COPD participants showed an initial increase in understanding, followed by a slight decrease. Given the less extensive course provided to COPD participants in this study, educational interventions for persons with COPD may need to be longer lasting in order to maintain an initially increased *understanding*. However, the importance of *understanding* may be dependent on other factors, such as perceived health status. In a study of cardiac patients, Karademas (2012) found that higher *understanding* was associated with higher optimism, but only in participants with lower levels of health. Resultantly, the relevance of accurate illness-related knowledge for a positive health outcome may be stronger for those with poorer health.

An accurate illness understanding includes perceptions about *timeline* as well as about illness *control*. Obese participants showed a linear decrease in expected illness duration. In

theoretical terms, this change represents a shift from a chronic towards an acute model of illness (Cameron and Leventhal, 2003). These participants may have experienced changes (e.g., healthier lifestyle, weight reduction, or improved physical fitness) during the follow-up period, which may have shifted their beliefs about the reversibility and likely duration of their illness. Combined with the increased *personal control* also observed in this group, the decreased *timeline* seems realistic and may increase the hope of improvement. Similar results have been found with other illness groups (Petrie et al, 2002). A randomized controlled trial with myocardial infarction patients showed that the intervention designed to change illness perceptions resulted in participants perceiving their illness as having shorter duration and being more controllable, compared to the control group. The patients receiving the intervention also returned to work sooner than the control group, a finding later replicated by Broadbent and colleagues (2009).

In contrast, COPD participants showed no change in *timeline*. Hopefully, effective coping strategies were learned and practiced during the course, but reversing the illness is not a realistic aim. To the contrary, these participants were taught about the progressive and incurable nature of COPD. The finding is consistent with results from an intervention study of patients with heart attack who did not change their view of illness duration after a patient education course in which chronicity was emphasized (Broadbent et al, 2009). Furthermore, COPD participants did not maintain their initial increase in *personal control*, as opposed to the linear increase in this domain observed among the obese participants. The different trajectories in this domain mirrors the results in a study of self-efficacy with the same sample (Bonsaksen et al, in review), and prior studies have similarly reported poor outcome maintenance among COPD patients (Heppner et al, 2006; Ries et al, 2003). More importantly, these perceptions can have long-term implications, as demonstrated in a study of osteoarthritis

patients associating perceptions of reduced illness control with poorer functional outcomes over a six-year period (Kaptein et al, 2010).

Both groups experienced reduced *treatment control* during the follow-up period. This may reflect a vanishing hope for improvements, and decreased *treatment control* has previously been shown to predict lower attendance rates in pulmonary rehabilitation (Fischer et al, 2009). However, it may also reflect a more realistic view of the situation. In support of this reasoning, subsiding perceptions of medical treatment as curative has been related to favorable outcomes in obese patients taking medication (Hollywood and Ogden, 2011) and in heart disease patients following angioplasty (Astin and Jones, 2006). Although a positive view of the treatment can be important, a reduced belief in a solely medical solution to their illness is a sound cognitive adaptation.

According to the CSM, the emotional burden of illness can be reduced by perceiving the illness as less threatening (Cameron and Leventhal, 2003). Therefore, the trajectories of *concern* and *emotional response* may be aligned with those for *identity* and *consequences*. Experiencing fewer symptoms and consequences over time, as occurred for the obese participants, would normally lead to less concern and other negative emotions. In a related vein, DeJong and colleagues (2012) found anxiety to be positively related to *consequences* and *emotional response* in a sample of persons with bulimia nervosa. Furthermore, the reduction of symptoms across time has been empirically related to the concurrent experience of fewer consequences (Astin and Jones, 2006). Reaching personal goals and leading a more fulfilling social life can be viewed as the contrast to experiencing consequences from illness, as argued in previous research (Fischer et al, 2010). Thus, perceiving fewer consequences can therefore increase hope and optimism and lead to better outcomes (Petrie et al, 2002). As seen with the COPD participants, on the other hand, unchanged symptoms and consequences provided no cause for reduced emotional distress.

Emotional representations of illness may also change as a result of changes in the person's appraisal of coping (Cameron and Leventhal, 2003). The implementation of coping strategies during the follow-up period may have been viewed as more effective by the obese persons. In other words, lifestyle changes (coping) that are appraised by the person as effective in combating obesity (the health threat) can lead the person to perceiving the illness as less threatening. These changed cognitions will likely have positive effects on the person's emotional well-being. Thus, there appears to be a relationship between increasing *personal control* and decreasing *concern* and *emotional response,* as shown for the obese participants. In contrast, COPD participants did not maintain their initially increased *personal control*, and their *concern* and *emotional response* remained unchanged.

Study limitations

The lack of control groups does not allow for inferring causal relationships. As a result, the trajectories for both groups in this study may have been affected by factors other than the patient education course. The nature of the illnesses investigated in this study likely account for some of the group differences. Although the educational courses for the obesity and COPD groups were largely equal in theoretical orientation and number of sessions, the obesity courses had longer duration (9 weeks) than the COPD courses (3-5 weeks). The longer lasting obesity courses may have contributed to more favorable trajectories in this group. Finally, given the large proportion of dropouts from the study, in addition to the differences regarding age and *emotional response* between the dropouts and study participants, questions may be raised about how well the results generalize to the study populations.

Clinical implications

Illness perceptions are important for adopting and maintaining coping behaviors, and for subsequent health status in persons with chronic illness. Thus, illness perceptions in

chronically ill persons should be assessed and, when appropriate, efforts should be made to encourage more adaptive perceptions. Supporting a sense of personal control over the illness seems particularly important. Although we cannot be certain about the role of the patient education course in this development, the long-lasting effect for the obesity group is noteworthy and supports the significance of the patient education course in its current form.

A decrease in *personal control* among COPD participants after the six-month follow-up suggests a need for health professionals to put more effort into fostering patients' sense of personal control (Arnold et al, 2006; Bentsen et al, 2010; Scharloo et al, 2000). Extending the course duration and including more methods for effectively coping with the illness may increase its impact on the COPD participants' *personal control*. Alternatively, more frequent sessions, or innovations like sending text messages to participants during the follow-up period, may also be beneficial (Petrie et al, 2012).

For both groups, *treatment control* declined across time. This may reflect hopelessness concerning the expected illness trajectory, but may alternatively indicate a need to increase personal control over self-management. If reduced belief in treatment is accompanied by an increased belief in the person's own ability to exert control over the illness, this may well increase the potential of self-management interventions for persons with chronic illnesses. Health professionals should support persons with morbid obesity and COPD in adopting the view that adherence to medical treatments is but one helpful aspect of coping with illness. Treatments for these illnesses must be accompanied by the person's self-management, and this should be emphasized in patient education.

Conclusion

Illness perceptions did change in participants with chronic illness during the first year following a patient education course. However, changes were different for participants with morbid obesity compared to participants with COPD. Differences between the illnesses and

their progression over time are likely to account for the different trajectories of illness

perceptions in the two groups. The results provide support for the Common Sense Model,

suggesting that perceptions of illness are distinct from, yet related to, emotional responses and

subsequent coping behaviors. The BIPQ appears well suited to assess group differences in

illness perceptions as well as trajectories of illness perceptions across time.

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Conflict of interest

The authors report no conflicts of interest.

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Table 1

Characteristics of the sample at baseline

	Obesity n = 53	COPD n = 52		
Sociodemographic variables	*M (SD)*	*M (SD)*	*ES*	*p*
Age	44.5 (9.5)	65.8 (9.0)	-2.30	<0.001
	n (%)	n (%)		
Male sex	13 (24.5)	29 (55.8)		0.001
Education > 12 years	18 (34.0)	15 (28.8)		0.57
In paid work	34 (64.2)	12 (23.1)		<0.001
Social environment	*M (SD)*	*M (SD)*		
Social support	4.0 (0.9)	4.3 (0.8)	-0.35	0.13
Illness perception				
Consequences	7.5 (1.9)	5.8 (2.3)	0.81	<0.001
Timeline	7.3 (2.5)	9.5 (1.3)	-1.10	<0.001
Personal control	4.1 (2.1)	5.0 (2.2)	-0.42	0.02
Treatment control	8.6 (2.0)	6.8 (2.4)	0.81	<0.001
Identity	7.2 (2.0)	6.2 (2.0)	0.50	0.02
Concern	7.8 (2.2)	5.8 (2.5)	0.85	<0.001
Understanding	7.7 (2.1)	6.9 (2.4)	0.35	0.08
Emotional response	7.1 (2.5)	4.6 (2.6)	0.98	<0.001

Note. Mean values (*M*), standard deviations (*SD*), and probability of differences (*p*) between the two subsamples as investigated with *t*-tests and χ^2-tests. Effect sizes (*ES*) are provided as Cohen's *d*.

Figure 1. Trajectories of illness perception domains in persons with morbid obesity (n = 53; dashed lines) and COPD (n = 52; solid lines)
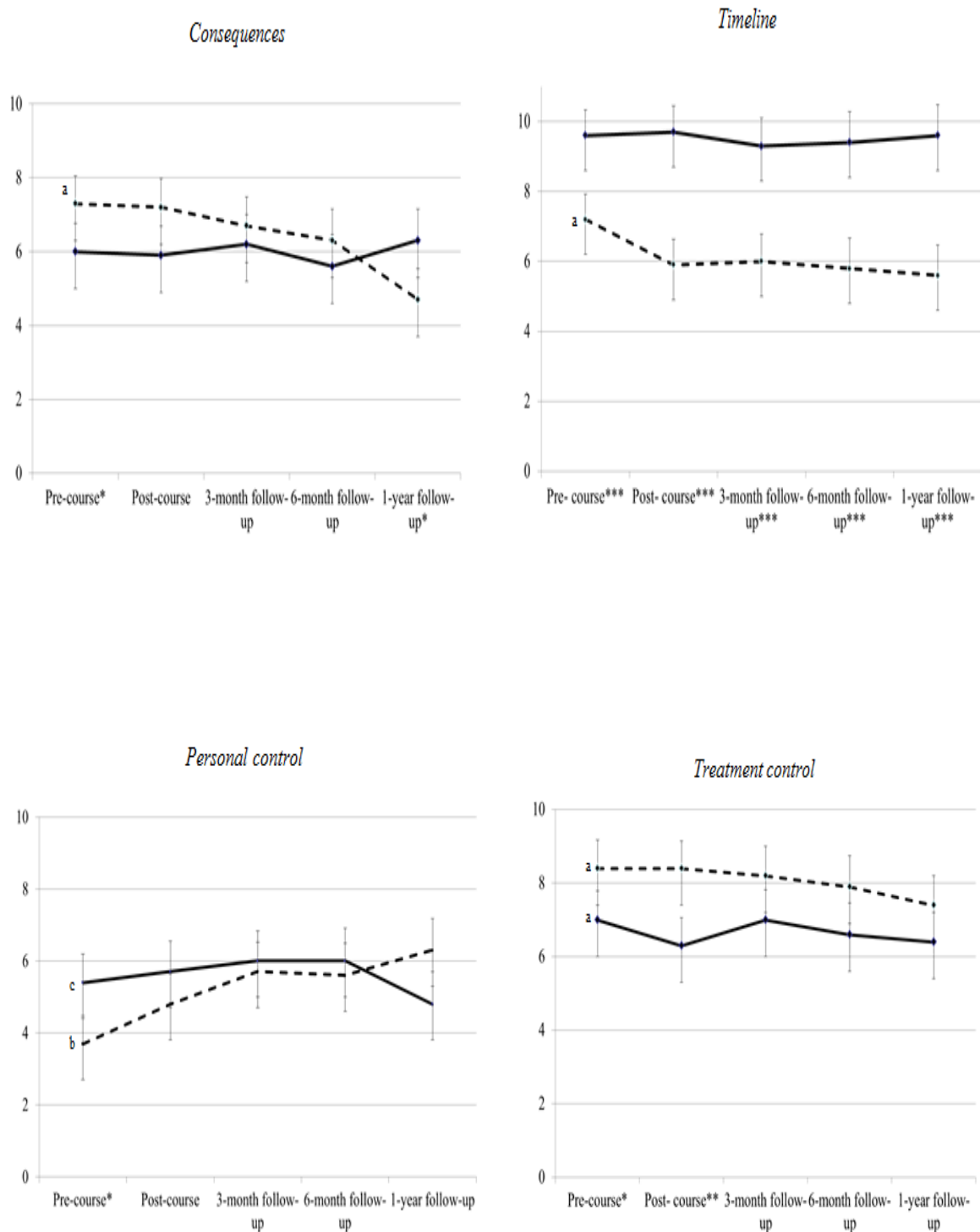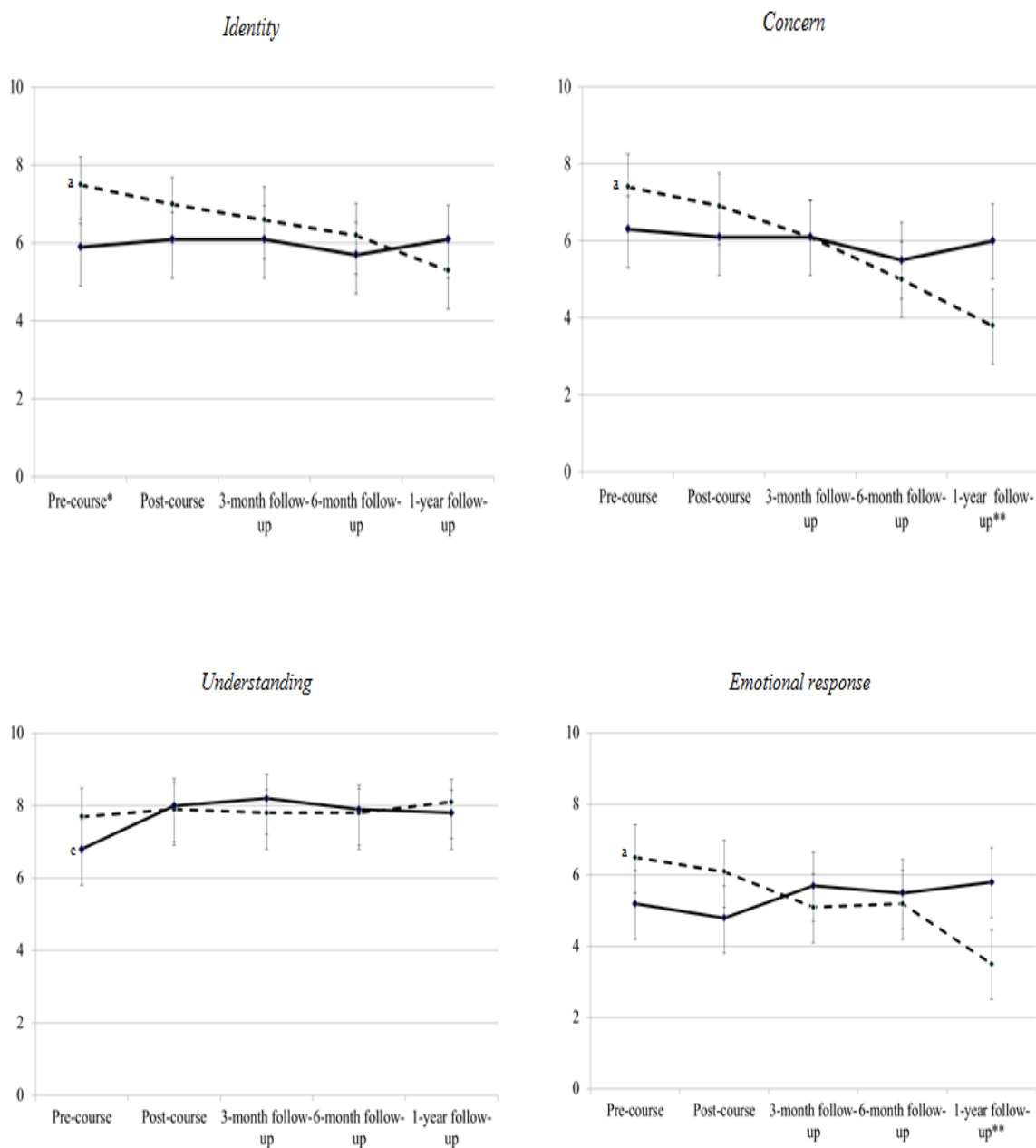
Figure 1 (continued).

Note. The figure shows the trajectories (estimated marginal means) of each illness perception domain in the sample, controlling for age and sex. Score range is 0-10, and bars indicate lower and upper 95% CI. a) significant linear decrease pattern; b) significant linear increase pattern, c) significant quadratic low-high-low pattern. Different mean values between the obesity and COPD groups at each time point are indicated with asterisks.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$