

Proposal master thesis on adaptation to chronic illness

Can time heal all wounds?

Anne de Hond

May 2017

1 Introduction

An accurate measure of the level of adaptation elicited by certain chronic health states can in practice be highly relevant. For example, the matter of adaptation has been of vital importance to the debate on health state evaluation affecting allocation of health care resources (Menzel, Dolan, Richardson & Olsen, 2002; Versteegh & Brouwer, 2016). The psychological processes underlying adaptation to positive or negative life events have captivated scientists and scholars for centuries. The evolutionary driven ability to adjust to new circumstances seems inherent to human behaviour, yet no empirical evidence to date provides unambiguous support regarding the occurrence or level of adaptation.

This apparent contradiction should not be surprising, since the study of adaptation is associated with many methodological complications. For example, many of the empirical findings are based on cross-sectional data, but in order to study the development of adaptation over time, panel data is required. Another complication arises when one wishes to measure adaptation to a particularly lamentable life event: chronic illness. The deterioration associated with these diseases when they are progressive (as is the case for rheumatoid arthritis and almost all cancers) complicate the measurement of adaptation, since the progressive debilitation is thought to have a negative effect on health state in contrast to adaptation (Frederick & Loewenstein, 1999). To quote Frederick and Loewenstein: “the hedonic deterioration that is commonly observed does not provide evidence that adaptive processes are not occurring - only that they are not occurring fast enough to keep pace with the progression of the disease” (1999, p. 312).

It is the aim of this thesis to study the extent to which adaptation occurs in several chronic (progressive) health states. In order to do so, the effects of progressive debilitation ought to be separated from those of potential adaptation. To this end, I propose using a fixed effects model, regressing self perceived health and well being on the incidence and duration of chronic illness. I expect the effect of duration on self assessed welfare to be positive, meaning that people adapt to their chronic condition over time, given that the patient’s health does not deteriorate. This study adds to the

existing research in that it makes use of panel data as opposed to the cross-sectional approach popular in the literature. Moreover, I will make use of the data provided by the SHARE database, which is more extensive and contains more control variables compared to most datasets used to carry out comparable analyses. Lastly, I will also address the question of measuring adaptation for progressive illnesses and not restrict myself to conditions with a relatively stable underlying state of health. To my knowledge, no research has been conducted taking the progressive nature of specific chronic conditions into account.

This proposal is build up as follows. Section 2 is concerned with a literature review on adaptation theory as well as an overview of the most important empirical findings on adaptation (to illness) and the methodological issues that have arisen. Section 3 provides a preliminary overview of the data from the SHARE project and section 4 contains the proposed methods. The last section provides a rough overview of the time frame in which I aim to finalize my thesis.

2 Adaptation theory and empirical research

2.1 Hedonic adaptation

While the academic study of adaptation is stemming from halfway the 20th century, the topic of relative happiness and wellbeing goes at least as far back as the Epicurean and Stoic philosophers of ancient Greece. The idea that human levels of happiness return to a relatively stable baseline after experiencing major positive or negative (life) events evolved into psychological theories of adaptation in the 20th century. Hence, the construct of adaptation is not exactly new, but the empirical evidence for the occurrence of adaptation is ambiguous and the extent of the adaptation is not well studied and highly debated (Oswald & Powdthavee, 2008; Frederick & Loewenstein, 1999). A review of the empirical evidence for adaptation follows below, but first a definition of adaptation will be given and expanded upon.

This thesis is concerned with what Frederick and Loewenstein (1999) have referred to as *hedonic adaptation*. Frederick and Loewenstein describe hedonic adaptation as “a reduction in the affective intensity of favorable and unfavorable circumstances” (1999, p.302). They identify two main functions of adaptation. First of all, adaptation protects the individual by lowering the internal impact of external stimuli. Furthermore, adaptation enhances perception by elevating the signal value produced by departures from the baseline level. A physiological example of this latter function is the adaptation our vision makes upon entering a dark environment. At first, we will not be able to differentiate subtle differences in hues, but after adapting to the low level of light we will be able to identify shapes and sizes. These two functions are also believed to govern hedonic states (hunger, thirst, pain etc.) leading to hedonic adaptation. Hedonic states are crucial as they alert our attention on pressing needs and avert us from engaging in dangerous activities. Nevertheless, prolonged exposure to a strong hedonic state (stress for example), is believed to have detrimental

physiological and psychological effects (Sapolsky, 1999). Hence, the ability to adapt may serve a protective function here. Additionally, if an aversive state is persistent, the perception enhancing function of hedonic adaptation might redirect motivation to productive changes in one's situation as opposed to lingering attempts to change the unchangeable. Thus, "adaptation provides the serenity to accept the things one cannot change, the courage to change the things one can, and the wisdom to know the difference" (Frederick & Loewenstein, 1999, p.303).

A more extensive operationalization of the processes that could lead to these productive changes is provided by Menzel, Dolan, Richardson and Olsen (2002). They identify the following eight elements. Firstly, people may simply acquire greater skills to achieve their exciting goals without adjusting them or the activities required to attain them. This is referred to as skill enhancement. Secondly, without changing their goals, people may change the activities enabling them to reach their goals, which is referred to as activity adjustment. Additionally, the goals themselves could be adjusted indicating substantive goal adjustment. Also, people might alter their conception of health. This means that a person adopts a different definition of health that is more productive in thinking about their state of health. For example, the humanistic conception of health construes that health should be evaluated in terms of one's ability to adapt to the problems in life, not by the biostatistical nature of the problems themselves (Nordenfelt, 1993). These first four elements were deemed by Menzel et al. to be admirable achievements in the light of the unfortunate circumstances in which they occurred.

The next three elements of adaptation are described as regretful (yet aiding the adaptation) and Versteegh and Brouwer point out that they are perception biases than an "adjustment of oneself" per se (2016, p.70). First of all, cognitive denial of one's functional health leads to a factually mistaken self-evaluation of health. Another cognitive deficiency classified as an element of adaptation is the suppressed recognition of full health, meaning that there is no acknowledgment of what it is like to be in full health and what type of possibilities that allows for. Thirdly, people can change their expectations regarding what level of achievement for a certain goal would be acceptable. These lowered expectations appear to be the least desirable out of all elements of adaptation. The last element is heightened stoicism and it is not deemed particularly admirable nor regrettable. Somewhat related to lowering expectations, heightened stoicism states that people come to evaluate their happiness by means of what is achievable. Hence, they realize that not coming as close to reaching their goals as they might have done previously does not have to impede their happiness.

2.2 Empirical research on adaptation

The extent to which adaptation occurs is a highly debated issue in the literature, with some researchers claiming to have found no adaptation at all and others a considerable amount. Of course, whether or not adaptation is present might be highly reliant on the nature of the event that is thought to be driving the adaptive processes. With this in mind, a review will follow on the most important empirical findings on adaptation to date, focusing on adaptation to disability and chronic illness.

Note that adaptation has mainly been studied within the field of psychology and is largely disregarded by the economics discipline (Oswald & Powdthavee, 2008). The most important reason for the absence of the notion of adaptation in the economics framework is that economists usually consider utility functions that do not take adaptation into account. This dichotomy between the two social sciences is remarkable, and in the current context of adaptation to disability, regrettable, since it might be a highly relevant factor in determining one’s quality of life.

Within the psychological literature, the presence of adaptation is often universally accepted (Diener et al., 1999). However, there only appears to be a small set of high-quality studies that have actually empirically examined adaptation (Frederick & Loewenstein, 1999). The most famous study by Brickman, Coates and Janoff-Bullman (1978) is easily misconstrued as proof that paraplegics are as happy as people with no functional limitations. To the contrary, Brickman et al. found that paraplegics were significantly less happy than the control group, but scored above the midpoint of the 5-point scale. Hence, they argue that the accident victims are happier than what might have been expected given their circumstances. Other researchers have come to similar conclusions. Tyc (1992) found that pediatric amputees seem to adjust remarkably well considering their limitations, with limb salvage patients not reporting a higher quality of life than amputees. Note that the definition of a “well-adjusted” individual varies wildly across the different studies discussed by Tyc, which makes the true psychosocial status of the subjects hard to compare. Paraplegics and quadriplegics also were reported to experience some degree of adaptation by Schulz and Decker (1985). They found that people suffering from spinal-cord-injuries had subjective levels of well-being only marginally lower than that of non-disabled people of the same age.

Since the study by Tyc (1992) did not have a control group available, only tentative conclusions can be drawn regarding the quality of life of these individuals in comparison with the public norm (as was done for the Brickman et al. results). A study by Dijkers (1997) does allow for this comparison with the general public. Dijkers performed a cross-sectional meta analysis for people with spinal cord injuries and found that affected individuals reported a lower subjective well-being than able-bodied individuals¹.

2.3 Methodological issues

It is important to point out several methodological limitations applying to most of the aforementioned studies. First of all, since we are interested in an adaptive process that is thought to develop over time, panel data is required. However, most studies investigating adaptation are cross-sectional and therefore only patients’ current level of well being can be compared with that of a healthy sample (Lucas, 2007). Moreover, most studies on adaptation are not prospective, meaning that they do not include the

¹Dijkers did not control for other factors that determine quality of life, particularly socioeconomic status, gender and age. However, he claims that the results are consistent enough to conclude that on average a person with spinal cord injury has a lower quality of life compared to somebody without injury.

onset of the illness or trauma of the patients in their sample. This is important since it allows us to compare the premorbid levels of well being with those after the debilitating event has occurred. Furthermore, even though disability due to chronic illness is thought to be largely exogenous (Oswald & Powdthavee, 2008), some selection bias might still be present depending on the disability. For example, even before the injury had occurred, burn victims were more prone to develop psychological disorders (Patterson et al., 1993; Tyc, 1992).

Hence, due to the issues mentioned above, cross-sectional data might be inappropriate for measuring adaptation. Moreover, a panel data study allows us to assess the development of adaptation over time for different individuals. A final methodological issue is the involvement of a stimulus that is most likely not constant (Frederick & Loewenstein, 1999). Specifically, it is probable that chronic illness will deteriorate over time, which leads to an opposite effect on well being than adaptation. Hence, additionally to measuring the onset of the illness, a variable should be present to measure the intensity of the illness as well.

3 Data

The data used for this study is obtained from the SHARE (Survey of Health, Ageing and Retirement in Europe) database. It consists of a self-completed survey whose “ultimate goal is to provide high-quality micro-level panel data of economic, social and health factors that accompany and influence ageing processes at the individual and societal levels” (Börsch-Supan et al., 2013, p. 993). The subjects are sampled from 18 European countries and Israel, with the eligibility of the subjects based on their age. Subjects of fifty years and over at the time of sampling were asked to participate in the SHARE project, whereas their spouse was asked to participate regardless of his or her age (SHARE Release Guide 6.0.0, 2017).

Waves 1, 2, 4, 5 and 6 are used for the current analysis ². The first wave (collected in 2004) consists of 30451 individuals, which expands to 68231 subjects in wave 6 (collected in 2015) ³. The total number of subjects and observations is given in table 1. Individual retention from wave 1 to wave 2 lies around 69%. From wave 2 to wave 4 this is 51%, which might be due to relatively more attrition in this longer interim. The retention rates between wave 4 and 5, and 5 and 6, is approximately 67%. Descriptive statistics regarding all observations in the consecutive waves are given in table 1.

In order to measure the effect of adaptation on quality of life two measures are employed. First, a self-perceived health measure is used, where satisfaction is measured on a 5-point scale (with 1 corresponding to excellent and 5 to poor). Secondly, the

²DOIs: 10.6103/SHARE.w1.600, 10.6103/SHARE.w2.600, 10.6103/SHARE.w4.600, 10.6103/SHARE.w5.600, 10.6103/SHARE.w6.600, see Börsch-Supan et al. (2013) for methodological details.

³Wave 3 is excluded because it diverges too much from the other waves and does not contain the variables of interest on physical health and quality of life.

CASP-12 index is used. CASP exclusively measures non-health dimensions of quality of life (Makai, Brouwer, Koopmanschap, Stolk & Nieboer, 2014), with higher scores indicating better quality of life, and a maximum attainable score of 48 (CASP, 2017). CASP includes questions like *“I look forward to each day”* and *“My age prevents me from doing the things I would like to”*. The two measures enable a comparison of the possible effects of adaptation on self-perceived health and on the more general construct of well-being. Descriptive statistics regarding both the self-perceived health and CASP measure can be found in table 1.

Table 2 contains an overview of the proportion of chronically ill subjects for all waves and a subdivision displaying the types of doctor diagnosed illnesses prevalent in the chronically ill subsample. Whether or not somebody is suffering from a chronic illness is asked as follows: *“Some people suffer from chronic or long-term health problems. By chronic or long-term we mean it has troubled you over a period of time or is likely to affect you over a period of time. Do you have any such health problems, illness, disability or infirmity?”* It becomes clear from the table that high blood pressure or hypertension are most prevalent amongst the chronically ill subjects, with more than half having received this diagnosis.

Table 1: SHARE data descriptive statistics

	Mean	Std. deviation
CASP-12	37.292	6.331
Self perceived health	3.149	1.091
% Chronically ill	50.912	
% Not chronically ill	48.751	
% Severely limited in activities	15.526	
% Limited but not severely	29.989	
% Not limited	54.151	
% Female	59.899	
Age	64.096	16.026
% Retired	54.043	
% Employed or self-employed	26.968	
% Unemployed	2.933	
% Permanently sick or disabled	3.502	
% Homemaker	9.931	
% Other	1.350	
Number of children	2.138	1.438
Household size	2.171	1.053
% Divorced	3.773	
% Married and living together with spouse	33.742	
% Married, living separated from spouse	0.636	
% Never married	2.619	
% Registered partnership	0.800	
% Widowed	7.341	
Total observations		260244
Number of subjects		120047

Table 2: SHARE data prevalence illnesses across waves

	% Total observations
Chronically ill	50.912
Heart attack	23.949
High blood pressure or hypertension	74.860
High blood cholesterol	45.037
Stroke or cerebral vascular disease	7.741
Diabetes or high blood sugar	24.265
Chronic lung disease	11.770
Asthma	2.439
Arthritis	10.019
Osteoporosis	4.107
Cancer or malignant tumor	9.838
Stomach or duodenal ulcer	9.288
Parkinson disease	1.559
Cataracts	16.025
Hip fracture	3.931
Other fractures	9.874
Alzheimer's disease	3.180
Benign tumor	0.691
Other affective or emotional disorders	6.411
Rheumatoid Arthritis	9.195
Osteoarthritis or other rheumatism	18.487
Chronic kidney disease	1.023

The number of total observations across waves and the proportion of chronically ill subjects with a subdivision regarding different diseases. Note that subjects often report having several of the illnesses outlined here.

4 Proposed methods

The proposed method is fixed-effects regression (by means of the within estimator) on the panel data set in line with the approach used by Clark, D’Ambrosio and Ghislandi (2016) and inspired by Cubí-Mollá, Jofre-Bonet and Serra-Sastre (2016) to measure adaptation to health states. The proposed linear model is given below:

$$y_{it} = \alpha_i + \beta_1 y_{i,t-1} + \beta_2 D_{it} + \beta_3 d_{it} + \beta_4 D_{it} C_{it} + \theta C_{it} + \varepsilon_{it}. \quad (1)$$

Here, the dependent variable y_{it} either represents the CASP-12 score regarding well-being or self-rated health of individual i in wave t . The time varying and individual specific covariates captured by C_{it} are age⁴, marital status, number of children, years of education, labour-force status, earnings from employment and self-employment. The individual fixed effects like gender and race are captured by the time invariant variable. Moreover, D_{it} is a dummy indicating chronic illness and d_{it} measures the duration of chronic illness.

If adaptation is indeed occurring, the estimated coefficient on the duration variable should be positive, indicating that the progression of time since the onset of a disease has a positive effect on well being. However, this will only be the case if the patient’s health remains relatively stable, since a deteriorating disease will obviously have an increasing negative effect on self assessed health or well being. In order to test this, I will select individuals with a wide range of chronic illnesses including those whose disease has been shown to be relatively stationary over time.

In the case when the chronic disease has increasingly detrimental effects on a patient’s health, the effect of adaptation is hypothesized to be harder to observe, since the positive effect of adaptation on well being may be cancelled by the negative effect of the debilitating disease. This poses a methodological challenge, requiring us to model the two effects accurately which allows one to study them in isolation. I propose to do this by including a lagged variable of well being or self assessed health $y_{i,t-1}$, which indicates the self perceived health state in the previous wave. This serves as a proxy for potential deterioration.

Furthermore, a chronic illness is likely to have a negative effect on socioeconomic factors like occupational disability that could result in unemployment. In order to capture this effect, interaction terms are included consisting of the chronic illness dummy and all socioeconomic variables included in the covariates C_{it} . When an increase in a socioeconomic factor corresponds with an increase in well being, I expect the coefficient on the interaction term to be negative, meaning that the incidence of chronic illness tempers the effect these socioeconomic factors have on well being. Alternatively, socioeconomic factors that negatively affect welfare (take unemployment) are also expected to have negative coefficients on the interaction terms, implying that the negative state is exacerbated by the presence of a chronic condition.

The SHARE data base provides simple hot-deck imputations for variables with nonresponse regarding negligible fractions and a multivariate imputation method for

⁴Age might be divided in age groups in line with the study by Clark, D’Ambrosio and Ghislandi (2016).

monetary variables (SHARE Release Guide 6.0.0, 2017). Moreover, five imputations have been made available to account for the additional uncertainty introduced by the imputation method. The imputed variables available to me are earnings from employment and earnings from self-employment, gender, age, years of education, self-perceived health, marital status, number of children, limitations in activities and employment.

Finally, I will shortly touch upon one of the most persistent methodological challenges, namely attrition between waves. The level of attrition is relatively high. As Börsch-Supan and colleagues (2013) point out, this is a common nuisance in face-to-face surveys. However, with respect to the current analysis, the attrition might not be occurring completely at random. In fact, it is likely that attrition is caused by endogenous factors leading to sample selection bias. For example, progressive chronically ill people are more likely to become deceased. Following the approach of Cubi-Mollá, Jofre-Bonet and Serra-Sastre (2016), I will test for endogenous attrition by means of the Verbeek and Nijman (1992) test. If the null hypothesis cannot be rejected, I will correct the model by means of the ex-post calibrated weights provided by SHARE and generated according to the approach of Deville and Särndal (1992).

5 Time frame

Table 3 contains my proposed planning for the remainder of the thesis.

Table 3: Planning

End of April/beginning of May	Hand in thesis proposal
May & June	- Finalize construction of the data set (including imputations and weights) - Perform analyses - Meeting(s) to obtain feedback on results and potential complications
End of June & July	Hand in final draft
July & August	Hand in final version thesis

literature

Bakx, P., Meijer, C., Schut, F. & Doorslaer E. (2015). Going Formal or Informal, Who Cares? The Influence of Public Long-Term Care Insurance. *Health economics*, 24(6), 631-43.

Börsch-Supan, A., Brandt, M., Hunkler, C., Kneip, T., Korbmacher J, Malter, F., Schaan, B., Stuck, S., Zuber, S.; SHARE Central Coordination Team. (2013). Data resource profile: The Survey of Health, Ageing and Retirement in Europe (SHARE). *Int J Epidemiol.*, 42(4), 992-1001.

Brickman, P., Coates, D. & Janoff-Bulman, R. (1978). Lottery winners and accident victims: Is happiness relative? *Journal of Personality and Social Psychology*, 36, 917–927.

CASP scoring and properties. (2017). *CASP-19: Measuring quality of life in later life*. Retrieved from: <https://casp19.com/casp-scoring-and-properties/>.

Clark, A.E., D'Ambrosio, C. & Ghislandi, S. (2016). Adaptation to poverty in long-run panel data. *Review of Economics and Statistics*, 98(3), 591–600.

Cubí-Mollá, P., Jofre-Bonet, M. & Serra-Sastre, V. (2016). Adaptation to health states: Sick yet better off? *Health Economics*, 1–18.

Deville, J.C. & Särndal, C.E. (1992). Calibration estimators in survey sampling. *Journal of the American Statistical Association*, 87, 376–82.

Diener, E., Suh, E. M., Lucas, R. E., & Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin*, 125, 276–302.

Dijkers, M. P. (1997). Quality of life after spinal cord injury: A meta analysis of the effects of disablement components. *Spinal Cord*, 35, 829–840.

Frederick, S. & Loewenstein, G. (1999). *Hedonic adaptation*. In: Diener, E., Schwarz, N. & Kahneman, D. (Eds.), *Hedonic Psychology: Scientific Approaches to Enjoyment, Suffering, and Well-Being*. Russell Sage Foundation, New York, pp. 302–329.

Kahneman, D. & Tversky, A. (1979). Prospect theory: An analysis of decision under risk. *Econometrica*, 47, 263–291.

Lucas, R.E. (2007). Long-term disability is associated with lasting changes in subjective well-being: Evidence from two nationally representative longitudinal studies. *Journal of Personality and Social Psychology*, 92, 717–730.

Makai, P., Brouwer, W.B.F., Koopmanschap, M.A., Stolk, E.A. & Nieboer, A.P. (2014). Quality of life instruments for economic evaluations in health and social care for older people: A systematic review. *Social Science & Medicine*, 102, 83–93.

Menzel, P., Dolan, P., Richardson, J. & Olsen, J.A. (2002). The role of adaptation to disability and disease in health state valuation: A preliminary normative analysis. *Social Science & Medicine*, 55, 2149–2158.

Nordenfelt, L. (1993). *Quality of life, health and happiness*. Aldershot, UK: Avebury Press.

Oswald, A.J. & Powdthavee, N. (2008). Does happiness adapt? A longitudinal study

of disability with implications for economists and judges. *Journal of Public Economics*, 92, 1061-1077.

Patterson, D. R., Everett, J. J., Bombardier, C. H., Questad, K. A., Lee, V. K., & Marvin, J. A. (1993). Psychological effects of severe burn injuries. *Psychological Bulletin*, 113, 362-378.

Sapolsky, R. M. (1999). *The physiology and pathophysiology of unhappiness*. In: Diener, E., Schwarz, N. & Kahneman, D. (Eds.), *Hedonic Psychology: Scientific Approaches to Enjoyment, Suffering, and Well-Being*. Russell Sage Foundation, New York, pp. 453-469.

Schulz, R. & Decker, S. (1985). Long-term adjustment to physical disability: The role of social support, perceived control, and self-blame. *Journal of Personality and Social Psychology*, 48(5), 1162-1172.

Survey of Health, Ageing and Retirement in Europe. (2017, March 31). Release Guide 6.0.0. Retrieved from: http://www.share-project.org/fileadmin/pdf_documentation/SHARE_release_guide_6-0-0.pdf.

Sprangers, M.A.G. & Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine* 48, 1507-1515.

Tyc, V. L. (1992). Psychosocial adaptation of children and adolescents with limb deficiencies: A review. *Clinical Psychology Review*, 2, 275-91.

Verbeek, M. & Nijman, T. (1992). Testing for selectivity bias in panel data models. *International Economic Review*, 33, 681-703.

Versteegh, M.M. & Brouwer, W.B.F. (2016). Patient and general public preferences for health states: A call to reconsider current guidelines. *Social Science & Medicine*, 165, 66-74.