

Combining Mindfulness and Ultraviolet Phototherapy (UVB) in the treatment of moderate Psoriasis. A Pilot Study of patients experiences of the disease and treatment.

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Abstract

We did a small pilot study with mixed method. The data collection included both quantitative data as well as qualitative data from interviews. We recruited sixteen moderate psoriasis patients divided in the following two groups of interventions (n = 8) and control (n = 8). The intervention group was given a brief Mindfulness practice as a supplement for the Ultraviolet Phototherapy. The control group received only Ultraviolet Phototherapy. The aim was to develop a design for examining the effect of mindfulness during light therapy. The dependent variables were quality of life, perceived stress, severity, facets/traits of mindfulness. The results were non-significant for any differences between the intervention and control group at baseline or follow-up. A significant difference was detected for perceived stress and quality of life between baseline and follow-up for both the intervention and control group, and it was likely because of light therapy. Qualitative data provided clear indications of improved subjective well-being in that practicing mindfulness compared to the control group. The acknowledgement of distress impact on the disease should lead to practical use stress reduction methods such as Mindfulness to prevent further stress aggravation of the disease. Mindfulness may be an emotional-focused coping, which reduces the physical response to the stressor, without altering the stressor. Interviews indicated a high threshold for seeking treatment, with reasoning for time consume and distance to light treatment. The instruments behaved as expected in the design, arguing for conducting a larger study.

Keywords. stress, Mindfulness, aggravating, well-being, light therapy, coping, emotional-focused coping.

Sammendrag

Vi gjorde en liten pilotstudie med ”Mixed method”. Datainnsamling inkluderte både kvantitative data samt kvalitative data fra intervjuer. Vi rekrutterte seksten moderate psoriasis pasienter i følgende to grupper av intervensjoner (n = 8) og kontroll (n = 8). Gruppen intervensjon ble gitt en kort Mindfulness praksis som et supplement for ultrafiolett lysbehandling. Kontrollgruppen fikk bare lysterapi. Målet var å utvikle et design for å undersøke effekten av mindfulness under lysterapi. Avhengige variabler var livskvalitet, oppfattet stress, grad av sykdomsalvorlighet, trekk av mindfulness. Resultatene var ikke betydning for eventuelle forskjeller mellom gruppen intervensjon og kontroll på opprinnelige eller oppfølging. En signifikant forskjell ble oppdaget for oppfattet stress og livskvalitet mellom første og andre måling for både intervensjon og kontrollgruppen, og det var trolig på grunn av effekten til lysterapi. Kvalitative data ga tydelige indikasjoner på forbedret subjektivt velvære for de som praktiserte mindfulness. Erkjennelsen av stress sin forverring på sykdommen bør føre til praktisk bruk av stress reduksjon metoder som Mindfulness for å hindre videre stress forverring av sykdommen. Mindfulness kan være en emosjonell-fokusert mestring, hvor den fysiske responsen blir redusert under stress, uten at en prøver å endre stressoren. Intervjuene indikerte en høy terskel for å søke behandling, begrunnet med tidsforbruk og avstand til lys behandling. Instrumentene for måling oppførte seg som forventet i vårt design, og det begrunner muligheten for en større studie.

Nøkkelord. stress, Mindfulness, forverring, velvære, lysterapi, mestring, emosjonell-fokusert mestring.

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Preface

The work of my master thesis was made possible by counsel from my supervisor and co-supervisors. The design was developed with supervision from Matthias Mittner , Florence Dalgard, and Ida Solhaug. Mattias Mittner accompanied me for the meeting at the Skin outpatient clinic at the University Hospital of Northern Norway UNN.

The REK application was completed with assistance from Matthias Mittner and Ida Solhaug. Any further changes regarding REK was made with aid from supervisor Svein Bergvik. The intervention was provided by Anne R.Grini and founded by Master funds.

The clinical assessment and recruitment of patients was done by the physicians Dagfinn Moseng and Øyvind Bremnes. Øyvind Bremnes and Nurses explained the Light therapy for the student. The practical and empirical part of this study, such as design of research questions, conducting interviews, collecting quantitative data, transcription, analysis, statistical work and writing was done by me.

The research search was mostly done by the student, though some literature were given by the supervisors. Svein Bergvik and Ellinor Ytterstad advised in the statistical part. The supervisors gave suggestions about the text during this period. Svein Bergvik suggested the specific randomization procedure for the study and Mixed methods with adding qualitative data.



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Psoriasis is a chronic inflammatory skin disease (Danielsen, Olsen, Wilsgaard, & Furberg, 2013). The most common version of this illness is Psoriasis Vulgaris, characterized by symptoms of red, scaly plaques. The disease affects the skin, nails and sporadically the joints. It is usually located at elbows, knees, and the scalp. The redness of the skin in psoriasis is due to an increased level of lymphocytes with amplified blood flow, better known as an inflammation. The precise mechanisms of psoriasis are still unknown, though psoriasis causes a higher frequency of skin cell productions and results in an incomplete outer layer of the skin, amplified blood flow, and lymphocyte infiltration (Health Quality, 2009; Kabat-Zinn et al., 2003; Kabat-Zinn et al., 1998)

A Northern European study reported 1.5 - 3 % prevalence of psoriasis (Bethany Fordham et al., 2013). A 30 years' follow-up cohort study in Tromsø, 2007-2008 found 11.8 % in age 20-79 years with psoriasis, compared to 4.8 % in 1979-1980 (Danielsen et al., 2013). A series of population based studies over three decades between 1970 to 2000, demonstrated that the prevalence of diagnosed psoriasis among ages >18 during was doubled (Icen et al., 2009). It has been argued that there seems to be a global rise in the disease at least documented in US and Norway (Icen M et al., 2009, Danielsen et al., 2013)

A major weakness of these studies is that they rely on self-report measures. The validated standard would be a diagnostic judgement by a trained clinical dermatologist. The diagnostic procedure of psoriasis performed by the dermatologist includes an evaluation of the following aspects of the outer layer of the skin: scaling, redness, thickness, and area of severity. The diagnostic procedure includes a clinical measure of Psoriasis severity. PASI (Psoriasis Area Severity Index) scales the severity of the disease with scores from 0-72 (Health Quality, 2009). It has been argued that future cohort studies should examine the prevalence of psoriasis with more rigorous study design and apply established and clinically validated diagnostic procedures of psoriasis performed by a physician (Bø et al., 2008; Danielsen et al., 2013).

Age onset and Climate influence

The age onset of psoriasis varies widely between studies, but there may be peaking bimodal age groups between 20-39 and 50-69 years (Rook & Burns, 2010). This may be due to various reasons, such as climate. The climate affects the disease, with increasing rates documented in some countries at higher latitudes. The climate's influence on psoriasis was also evident in a study from Minnesota with relatively more (68 % of cases) diagnosed during

winter and spring months (Cox, 2010). The effects of seasons may also be beneficial for psoriasis in the summer due to sunlight exposure (Bethany Fordham et al., 2013; Kabat-Zinn et al., 1998; Rook & Burns, 2010). Unfortunately, seasonal variations are not widely controlled for in clinical psoriasis studies. Future research is recommended to control for seasonal variations, based on the documentation of its importance and relevance in predicting the clinical outcome measures of severity (Bethany Fordham et al., 2013; Vedhara et al., 2007).

Ultraviolet Phototherapy (UVB)

Ultraviolet phototherapy was licensed in 1993 in Canada. Ultraviolet phototherapy is an effective treatment for moderate to severe psoriasis. This certain treatment is an good option when other topical treatments fails, like dithranol, calcipotriol (vitamin D analogue), and corticosteroids(cortisone) (Cox, 2010). A literature review of impact studies estimated ca. 70 % clearance rate, though the studies had small sample size with large confidence intervals. The number of needed treatment to clear symptoms is about 25 sessions (Archier et al., 2012). Light treatment requires an extended commitment of the patient, following treatment procedure over six-eight-weeks, with three sessions per week.

An extensive study followed 851 psoriasis patients in phototherapy, 53% received fewer than 20 treatments, and just about one-third received less than ten treatment sessions. The patients lived within 1- 20 km of the Phototherapy center. Only 47% completed the prescribed treatment necessary to obtain a 75 % improvement or clearing. The reasons for a lowered adherence is hugely due to time consume, resources and age (Kalia et al., 2014).

The specific pathological pathways of the disease are unclear, but the examining of medications and other treatment methods leads to a better understanding of illness and questions of cause and effects. Other treatments such as psychological interventions have also demonstrated significant effects on skin diseases (Lavda, Webb, & Thompson, 2012).

Psychological distress and burden of living with Psoriasis

Stress is documented by global research of Dermatology to contribute to aggravating the severity and reducing the life quality of psoriasis- patients (Dónal G. Fortune, Richards, Griffiths, & Main, 2002; D. G. Fortune et al., 2002; Griffiths, 2014; Griffiths & Richards, 2001; Kabat-Zinn et al., 1998; Rook & Burns, 2010; Seneschal, Clark, Gehad, Baecher-Allan,

& Kupper, 2012). The distinction for responding to stress was examined in Massachusetts health care system with 4576 subjects with a quantity of different diagnoses such as psoriasis (Koo, Do, & Lee, 2000). The subjects reported the time between the emotional trigger of stress and the clinical change of the disease. The psoriasis population reported days between the distress and the aggravating of the condition (Koo et al., 2000).

A review divides the stress of psoriasis, into the distress of the disease itself, consequences of the disease on quality of life and other psychosocial comorbidities like depression, anxiety, and suicidality. They suggest that Psychosocial comorbidities may increase the psychosocial stress and thus be an important factor in aggravating psoriasis (Hunter, Griffiths, & Kleyn, 2013). A recent cross-sectional study of 13 European countries examined the psychological burden of living with a skin disease (Dalgard et al., 2015). The interesting results regarding psychosocial comorbidities was a significant clinical anxiety on 17 % among people with psoriasis, and only this skin disease group reported suicidal thoughts (Dalgard et al., 2015). People with psoriasis report having higher levels of anxiety, depression, suicidal thoughts, and reduced quality of life compared to healthy populations (Olivier et al., 2010).

The reactions to stress depend on how the stressor is perceived by the individual. Patients who have high disease worry are less expected to clear the skin from symptoms than those with low-worry (Hunter, Griffiths, & Kleyn, 2013). Fortune and colleagues summarized that light therapy improved psoriasis specific factors such as disability and disease-related stress, but didn't influence the psychological well-being (Fortune et al., 2004).

Feelings of shame or embarrassment may well result in avoiding public places or locations where the skin is visible, therefore decreasing social activity, and even employment opportunities (Ginsburg & Link, 1993; Kimball, Jacobson, Weiss, Vreeland, & Wu, 2012) (Hrehorów, Salomon, Matusiak, Reich, & Szepietowski, 2012) The exact mechanism how stress influence psoriasis is unclear, but there seem to be an increased body of research on the effects of stress on psoriasis both within the dermatology and interdisciplinary fields (B. Fordham, Griffiths, & Bundy, 2015; Hunter et al., 2013; Kabat-Zinn et al., 1998)

Appraisals of Psychological stress

The tension of stress may be physical or psychological. The physical stressors to the skin is cold, heat, infections, or any harmful substances. Psychological stressors are events

that are not necessarily dangerous, but they are interpreted as a threat in our thoughts, perceptions and judgements. In daily life, we encounter events which can be physical and psychological, threatening challenging or something totally irrelevant. These judgements are primary appraisals accordingly to the model of Lazarus and Folkman (1984) (Lovallo, 2015). The primary appraisal is likely there for keeping us away from any immediate danger, by planning and adapting accordingly. The threat is founded on the primary beliefs of how the world should be and our commitments to courses of action. The secondary appraisal is the evaluation of our options in terms of coping with the threat. Lazarus and Folkman have defined coping behaviors as problem focused and emotion focused coping. Problem focused is about changing the issue directly, with behavior to change the event, or alter the beliefs and commitments. Emotional-focused strategies are about reaching out for psychological resources to alter the magnitude of the emotional response, rather than changing the event itself (Lovallo, 2015). The psychological response in emotional-focused coping leads to biological responses, which influence the autonomic nervous system, endocrine, and the immune system. The effects of the biological response of stress will then, contribute to the primary beliefs as it would be with experiences of stress (Lovallo, 2015). The two sets of copings have its limitations and strengths. Problem-focused seems to have major limitations in the matter of time and energy required to cope with the event, but it probably diminish the stressor value. An example is stress at work, and by being problem-focused with removing yourself from work it would reduce your stress, but it would be a change with cost. Emotional focused coping is less time consuming, though it tends to reduce coping resources and no influence on the event itself. In particular in stressful situations, where the stressor can't be changed or alter, is it perhaps more suitable to change the relation to the stressor with emotional-coping and in that process change the belief about the stressor at next encounter (Lovallo, 2015).

Stress reduction and Mindfulness

Mindfulness is originated from Buddhism and may be at least 2550 years old tradition (Keng, Smoski, & Robins, 2011). In the western society, Mindfulness is rather more new phenomena, as it was first studied as an intervention in medical and mental health settings during the beginning of 1970. The word mindfulness may describe a psychological trait, a practice of propagating mindfulness (Mindfulness meditation), a state of awareness, or a mental process (Keng et al., 2011). Most literature defines mindfulness as a non-judgmental attention to experiences in the present moment (Shigaki, Glass, & Schopp, 2006). The

definition is well adapted to the concept of mindfulness; however, it lacks in clarifying the specifics of mindfulness as a trait, practice, state, or process.

There are different kinds of mindfulness interventions as the 8-week group Mindfulness based stress reduction (MBSR) and Mindfulness based Cognitive Therapy (MBCT) (Fjorback, Arendt, Ørnbøl, Fink, & Walach, 2011). MBSR have formal practices of sitting meditation, body scan and mindful Yoga, and combining this in the informal process of coping with physical symptoms such as stress and challenging emotional contexts.

The participants in such courses have approximately practiced 10 hours of Mindfulness in groups as well as individually with recommendation of 45-60 minutes daily training. MBSR is an supplement for medical treatment, and MBCT is an prevention program (Fjorback et al., 2011). In home intervention, participants are more likely to differ in time and regularity practicing mindfulness and thus the need for reporting time and frequency (Vettese, Toneatto, Stea, Nguyen, & Wang, 2009). Mindfulness practice has shown benefits on symptoms of heart disease, chronic pain, depression, stress, cancer, and anxiety (Bohlmeijer, Prenger, Taal, & Cuijpers, 2010). The intervention often result in better subjective well-being (Keng et al., 2011).

Jon Kabat-Zinn stated in a documentary called "The Connection" that he was having lunch with some physicians, who told him about patients giving up on their treatments, and in particular those with the skin disease psoriasis. In 1998, he and colleagues examined the influence of brief mindfulness intervention for psoriasis patients treated with light therapy (Kabat-Zinn et al., 1998). They received a mindfulness intervention by audio tape during the minutes in the light booth. The participant was asked to follow instructions from moment to moment with a non-judgmental awareness.

The treatment lasted for 13 weeks and three sessions per week. The participants were clinically rated by their symptoms and photographed every fifth treatment. The control group received treatment as usual. The intervention group had a significant ($p = .033$) faster endpoint of clearing from the symptoms compared to the control group. There was no significant difference between the intervention group and the controls regarding depression and anxiety. Kabat-Zinn replicated the study in 2003, where he got the same results of significant results of faster clearing for those practicing mindfulness during light therapy ($p = .033$) (Kabat-Zinn et al., 2003). The major weaknesses of the Kabat-Zinn studies were the

lack of any objective clinical assessment, measurement of perceived stress, and instrument for measuring Mindfulness.

The Five Facet Mindfulness Questionnaire (FFMQ) is a valid instrument measuring dimensions of mindfulness. FFMQ includes the following five facets : a) “observing” is detecting the internal and external experiences; b) “describing” is phrasing the inner experiences with words; c) “acting with awareness” is regarding the attention of the present moment; d) “non-judging” of inner experience is defined as not evaluating thoughts and feelings; e) “non-reactivity” to internal experiences, concerns the approval of thought circulation and feelings without being held or carried away.

Few studies have examined the effect of mindfulness on psoriasis (Kabat-Zinn et al., 2003; Kabat-Zinn et al., 1998). Fordham performed a mindfulness based cognitive therapy on psoriasis patients at a skin clinic. Thirty patients were randomized to a control or an intervention group. The control group received treatment as usual. Patients with psoriasis arthritis were excluded. Mindfulness based cognitive therapy is aiming to detach the bodily sensations from the cognitive mind and thus, increase the acceptance of the physical state. The study measured Perceived stress, Self-Assessed Psoriasis Area Severity Index (SAPSI), and quality of life and performed the therapy in the summer. The results gave no significant changes in perceived stress, but a significant difference for self-reported psoriasis severity (38 %) and quality of life. The authors conclude the encouraging nature of their results but also, assert that the low number of participants prevents them from drawing definite conclusions. The weakness of this research is not using PASI, considered more objective than the SAPSI (self-assessed psoriasis severity index).

Given the few studies on the effect of mindfulness in psoriasis treatment, there is a need to reassess the impact, including clinical assessment of patients, instruments of Mindfulness, and logs for the amount and regularity practicing mindfulness (Vettese et al., 2009). To our knowledge at the current moment, we are the first in Norway to study the effect of mindfulness during light therapy for moderate psoriasis patients. We followed four endorsements from Fordham et.al 2013: a) seasonal variations, b) PASI, c) reported years having Psoriasis, d) The intervention developer was chosen in criteria of experience and skill performing mindfulness intervention(B. Fordham, Griffiths, & Bundy, 2013). The aim for this pilot study was to develop a study design for assessing the effect of Mindfulness intervention combined with Ultraviolet Phototherapy(UVB) in moderate psoriasis patients.

Method

Sample and recruitment procedure

Two physicians recruited among patients referred to Narrowband- Ultraviolet Phototherapy at the Skin outpatient clinic at the University Hospital of Northern Norway UNN during the months September-January 2016.

Patients were informed of the study during consultation with the physician and received an envelope including written information and a consent form. The physicians selected patients following the five inclusion criteria's: a) 18-60 years of age; b) Able to read and write Norwegian; c) A psoriasis diagnosis; d) Planned narrowband UVB-treatment at the Skin outpatient clinic at UNN Tromsø; e) Low to moderate psoriasis(PASI \leq 12).

Following the consultation, accepting patient signed the consent form and returned the envelope to the clinic. The student researcher contacted the patients for additional information. The physicians gave each participant a unique ID-number, labeled inside the envelopes. Only the project staff had access to the key linking the ID number to the name of the patients. The patient's ID numbers were randomly assigned to either the intervention or the control group. The patients received a sealed envelope with their ID numbers on the front and information about the given group inside. The physicians chose and handed to the patient one envelope from a stack of prepared envelopes and remained blind to which group each patient were assigned to. Twenty patients accepted to join the study. They were randomized to 11 and 9 patients to the intervention and control study respectively. Due to dropouts, the group sizes completing the study were 8 in each group. Reasons for dropout were a lack of motivation for mindfulness or no time for six weeks' light therapy.

Intervention

Mindfulness training audio -files were developed and provided by Mindfulness based-stress reduction Instructor Cand.polit Anne.R Grini. The audio file contained four tracks. The first track was an introduction to mindfulness training. Two tracks were sitting meditations, where one adapted the perspective of treating the skin. The last track was a body scanning. The tracks lasted between 4-19 minutes and the file was in 38 minutes in total.

Two sitting mediations, which one adapted the perspective of the treating the skin. Thirdly the body scanning. The tracks lasted in between 4-19 minutes and total 38 minutes.

The participants were invited to alternate among these four audio files throughout the intervention period of six weeks. The student researcher presented the intervention to each of the patients of the intervention group separately, and they were introduced to and invited to use visual instructional videos provided online by the headspace.com. The Headspace is a mindfulness app for English users. They logged their exercises on a record sheet. The student researcher offered instruction and practice in a room at the hospital, close to the clinic. The intervention patients were recommended to perform the exercises at home daily. Three chose to do exercises in the assigned room at the hospital when visiting the clinic for their light therapy.

Narrow-band Ultraviolet Phototherapy(NB-UVB)

The patients(N=16) used the following two machines (brand Waldmann): UV7001K and UV7000. UV7001K had a small proportion of UVA, but overall most UVB light. UV7000 had 100 % UVB-light. The wavelength was 311 nm for the mentioned devices. The most common criteria of effect are clearance rate, reduction in PASI (clinical assessment), and the number of treatments to clear. A literature review of impact studies estimated ca. 70 % clearance rate, though the studies had small sample size with large confidence intervals. The number of needed treatment to clear symptoms is about 25 sessions (Archier et al., 2012). Assessment of skin is done by the Fitzpatrick skin types from one-six. The skin type assessment maximizes the effect of NB- UVB while reducing the risk of burning. Physicians assessed the skin type of the participants as within the 1-2 range.

The recommended start-dose for skin type 1- 2 is 0.2 Joule/ cm², which is the energy(Joule) of UV-light put into each square inch(cm²) of the skin. Type 1-2 prescribes increase of 0,1 Joule/ cm², though the need for regulation due to individually reactivity to UVB- treatment. The machines are programmed to calculate the time by conditions of dose, previous use of the device, and the temperature in the room. 18 sessions were distributed into three sessions a week. The time under treatment had an interval from few seconds to several minutes at the end.

Clinical assessment

The physician evaluated the severity and area of disease with PASI (Psoriasis area severity index). The assessment differentiates between the following four sections of the body (head, trunk, upper and lower extremities) and the average assessment of these areas

representing the body surface area are multiplied by a severity score. The proportions of skin affected in each of the four body sections are coded into the following (0-9 %, 10-29 %, 30-49 %, 50-69 %, 70-89 %) and rated on a severity score from 1 to 6. The severity of three of the symptoms (redness, thickness, scaling) are evaluated on a 5-point scale: 0 (none), 1 (mild), 2 (moderate), 3 (severe), 4 (very severe). PASI is commonly used in dermatology clinics for its good reliability and validity in measuring the severity of psoriasis (Cabrera, Chinniah, Lock, Cains, & Woods, 2015; Lane et al., 2016). The PASI assessment correlates with SAPASI (self-reported psoriasis area severity index) and other measurement of severity (Gottlieb, Chaudhari, Baker, Perate, & Dooley, 2003; Health Quality, 2009; Lane et al., 2016). Three clinical assessments with PASI were completed for every patient; at the first consultation, after three weeks, and at six weeks.

The questionnaire

The patients completed a questionnaire with demographic data on gender, age, their highest completed education, time since their holiday in warm climate, weight, height, and their use of steroid cream at baseline and follow-up. The participants also completed the Perceived Stress Scale (PSS), Dermatological Life Quality index (DLQI), and the Five Facet Mindfulness Questionnaire short form (FFMQ-SF) at the start and after six weeks. The participants labeled their ID-number on the questionnaire.

Perceived Stress Scale (PSS) is a ten item questionnaire, which measures self-reported stress during the last month. Individuals respond to each item with scores Ranging from 0-4. Sum score is ranging from 0 to 40, with a high score indicating high amount of perceived stress. The instrument is validated in a range of studies of various populations and countries across the world (Cohen, 1983).

Dermatological Life Quality Index (DLQI) is a validated dermatology quality of life instrument with ten items measuring the impact of skin diseases on the daily life of a patient. The scoring goes from 0 to 31, scores up from 11 is assumed to have a large effect on the patient's life. The instrument is validated for measuring the life quality of individuals with skin diseases (Finlay & Khan, 1994). The authors from Cardiff University provided us license (ID CUQoL1134) for the use of their Norwegian translation of DLQI.

Five Facet Mindfulness Questionnaire(FFMQ) is originally 39 items, but this study used the FFMQ-SF with 24 items. Items were scored on a five-point Likert-type scale ranging

from 1 (never or very rarely true) to 5 (very often or always true). FFMQ-SF scores ranges from 5-25(except for Observe 4-20). Higher scores are associated with greater degree of mindfulness. Low scores of Mindfulness is related with higher distress (Bohlmeijer, ten Klooster, Fledderus, Veehof, & Baer, 2011; Montgomery, Norman, Messenger, & Thompson, 2016).

The instrument(FFMQ-SF) contains the following core characteristics of Mindfulness: Observe, Describe Actaware, Nonjudge and Nonreact. Baer et al.,2008 has combined the characteristics of several self-report measures of mindfulness into one instrument (Bohlmeijer et al., 2011). FFMQ has demonstrated acceptable internal reliability between the characteristics of Observe, Describe, Actaware, Nonreact, and Nonjudge. The author Baer et al., 2008 examined the construct validity through confirmatory factor analyses and by comparing FFMQ to measures of psychological symptoms, well-being, experiential avoidance and other personality factors (Baer et al., 2008; Bohlmeijer et al., 2011). Both the FFMQ and FFMQ-SF (short version) are reliable and valid for comparing FFMQ scores between meditators and non-meditators, in depressed adults and non-depressed (Baer et al., 2008; Montgomery et al., 2016). FFMQ has recently been used in psoriasis population (Montgomery et al., 2016).

The outcome variables were FFMQ, PSS, PASI and DLQI. The expected results for the intervention group were larger FFMQ scores and reduced PSS. The decreased PSS for the intervention group was expected to lead to greater reduction in PASI and DLQI. The patients were invited to write a comment at the end of the study.

Analysis

The data was made anonymous with an ID code to SPSS file. SPSS 24 was used to analyze the material. Demographical variables were all tested with independent -sample t-test for any differences at baseline, and levenes test variance. Paired-sample t-test were performed to check differences between baseline and follow-up for PSS, DLQI, and FFMQ-SF. Independent T-test was conducted for PSS, DLQI, and FFMQ-SF to check differences at baseline and follow-up.

We analyzed PASI with mixed ANOVA repeated measures. Assumptions of the mixed ANOVA repeated measures was checked with Levenes test of variance, Mauchly's Test of Sphericity, and test of homogeneity.

Ethics

The Regional Committee for Medical Research Ethics in Norway (REK Nord 2016/982) approved the study protocol, and the project was registered by the local Data Protection Official for Research at the University Hospital of North Norway (UNN). The accepting patients signed an informed consent form for the study and a separate informed consent form for the interviews. The student researcher and fellow research assistant signed a confidentiality statement.

Qualitative interviewing

The participants were invited to a qualitative research interview after six weeks. Five patients accepted, including three intervention and two control patients. The interview was organized as a semi-structured interview, based on an interview guide. It lasted approximately one hour and was audio recorded. The student researcher transcribed and coded the recordings. The background for the researcher's perspective is from having a chronic skin disease. The qualitative analysis of the transcript was based on the principles of Interpretive Phenomenology Analysis (IPA) (Osborn & Smith, 2008).

IPA is grounded on the three principles referred to as idiographic, hermeneutics, and phenomenology. Idiographic, as it carefully studies individuals case by case. Hermeneutic, as it focuses on meaning making processes and how individuals make sense of events in their life. IPA further refer to a double interpretation, involving processes of interpretation in the patient making sense of his/her situation, as well as in the scientist/interviewer interpreting what the patients communicate (Osborn & Smith, 2008). Finally, IPA is phenomenological, as it aims for getting a common meaning for several individual's experiences in a concept or phenomena, such as treatment, healing and illness.

The analysis in IPA includes careful and in-depth examining individuals case-by case, moving on to a correspondingly focused examination of the second patient, and so on, and subsequently merging the analysis of each case into the analysis of the complete set of cases. The analysis followed five steps: 1) a word-by-word transcription of the interviews, 2) detailed reading and identifying the various topics, 3) breaking up data into units of meaning, 4) reorganizing the data, drawing on categories of meaning emerging from the data and 5) the synthesis of the data through the writing process. NVIVO program was used in process of

grouping statements. The author and supervisor translated the applied statements. Applied statements were translated by the author and supervisor.

Although the quantitative and qualitative data were analyzed separately, it was followed by applying a mixed method approach, in which the interview results were related to the quantitative data of life quality, perceived stress, treatment, process of healing, and mindfulness.

Ethics for Interviews

All recordings were deleted after the transcription. The informants signed an own informed consent for attending the interview. The researcher gave each informant a pseudonym, however the commentary had single letters. Details shared in the transcription was removed in terms of location, work place, names and other sensitive information.

Results

The aim for this pilot study was to develop a study design for assessing the effect of Mindfulness intervention combined with Narrow-band Ultraviolet Phototherapy(UVB) in patients with moderate- psoriasis. The outcome variables were FFMQ, PSS, PASI and DLQI. The expected results for the intervention group compared to control were larger FFMQ scores and reduced PSS. The decreased PSS for the intervention group was expected to lead to greater reduction in PASI and DLQI.

Demographic

We checked for any differences in the baseline data between the intervention and control group. We found no difference between the groups on any of the tested variables. The mean age was not significant different, but a tendency for larger age in the intervention compared to the control. The study consisted mostly of women. The secondary diseases were examples of cancer, Bekhterevs syndrome/ ankylosing Spondylitis, arrhythmias in heart, Chronic Skin infection, and Hirsutism. The use of steroid cream was reduced as the table illustrates. See table 1.

The clinical measurement presents a tendency to distinguish between climate and time since exposure to warm or cold temperatures. See figure 1.

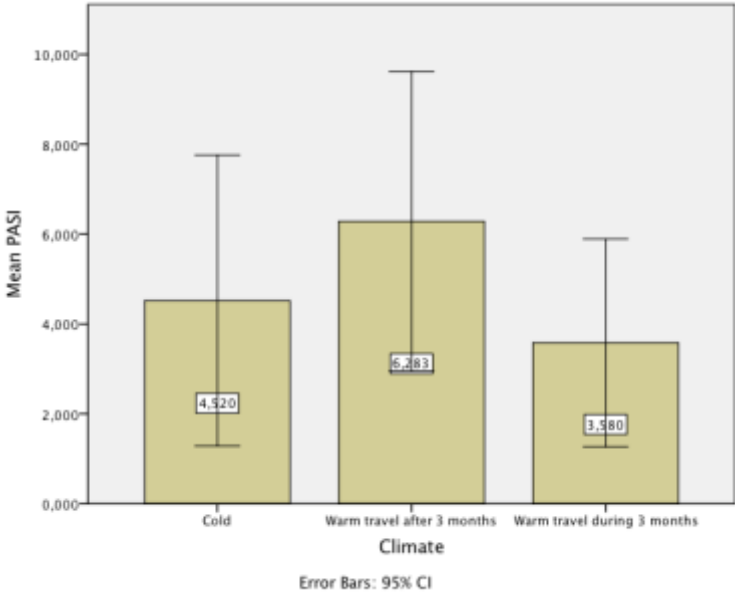


Figure 1. Clinical measure(PASI) and travel in warm or cold environment for the last 3 months

Table 1. Demographic with SD, and p-values at baseline.

	Control		Intervention		All(N=16)	<i>p</i>
	<i>N</i>	<i>M (SD)</i>	<i>N</i>	<i>M (SD)</i>	<i>M (SD)</i>	
Age	8	38.2 (7)	8	47.5 (10.9)	42.8 (10.8)	.06
Female %	8	4 (50%)	8	5 (62.5%)	9 (56.3%)	
High Education %	8	6 (75 %)	8	7 (87.5 %)	13 (81.3 %)	
Years with Psoriasis	7	20.4 (7.6)	8	19.7 (13.6)	20.1 (10.8)	.91
Weight	8	75.6 (21.4)	8	77.6 (17.8)	76.6 (19.1)	.84
Height	8	173.8 (6)	8	168.3 (8.3)	171.1 (7.5)	.15
BMI	8	24.8 (5.9)	8	27.1 (3.8)	25.9 (4.9)	.37
Secondary Disease %	8	3 (37.5 %)	8	1 (12.5)	4(25 %)	
Baseline Steroid %	8	5 (62.5 %)	8	6 (75 %)	11(68.7%)	
Follow-up Steroid %	8	1 (12.5 %)	7	4 (57.1 %)	5(33.3 %)	

Note. *SD* = standard deviations, *p* = statistical significance.

Table 2. Paired-sample t-test between Baseline and Follow-up				
		Baseline <i>M(SD)</i>	Follow-up <i>M(SD)</i>	<i>p</i>
FFMQ-SF				
N=8 control		15 (3.7)	14.4 (1.6)	ns
N=7 Intervention	Observe	14.4 (3.5)	15.1 (1.1)	ns
N=8 control	Describe	19.3 (2.3)	19.8 (3.1)	ns
N=7 Intervention		17.8 (3.7)	18.8 (3.3)	ns
N=8 control	Actaware	19.5 (2.4)	18.5 (3.5)	ns
N=7 Intervention		17.6 (4.5)	17 (3.7)	ns
N=7 control	Nonreact	14 (3)	13.5 (5.5)	ns
N=7 Intervention		15.3 (4.3)	17.30	ns
N=7 control	Nonjudge	16.6 (2.8)	16.1 (4.5)	ns
N=7 Intervention		16.5 (3.2)	14.8 (1.34)	ns
N=8 control	PSS	18.7 (5.2)	11.7 (4.9)	.001**
N=7 Intervention		15.3 (4.5)	12.5 (6.0)	.04*
N=8 control	DLQI	10.7 (6.2)	2.8 (3.1)	.001**
N=7 Intervention		9.6 (5.6)	5.4 (5.5)	.04*

Notes. FFMQ-SF= Mindfulness instrument, PSS= perceived stress, DLQI= Life quality, SD= Standard deviation, ns= non-significant, * $p \leq .05$, ** $p \leq 0.001$

Table 3 inter-item-reliability of FFMQ-SF

FFMQ-SF	Number of items	<i>Alpha</i>
Observe	4	0,81
Describe	5	0,78
Actaware	5	0,78
Nonjudge	5	0,55
Nonreact	5	0,83

Note. FFMQ-SF= Mindfulness instrument.

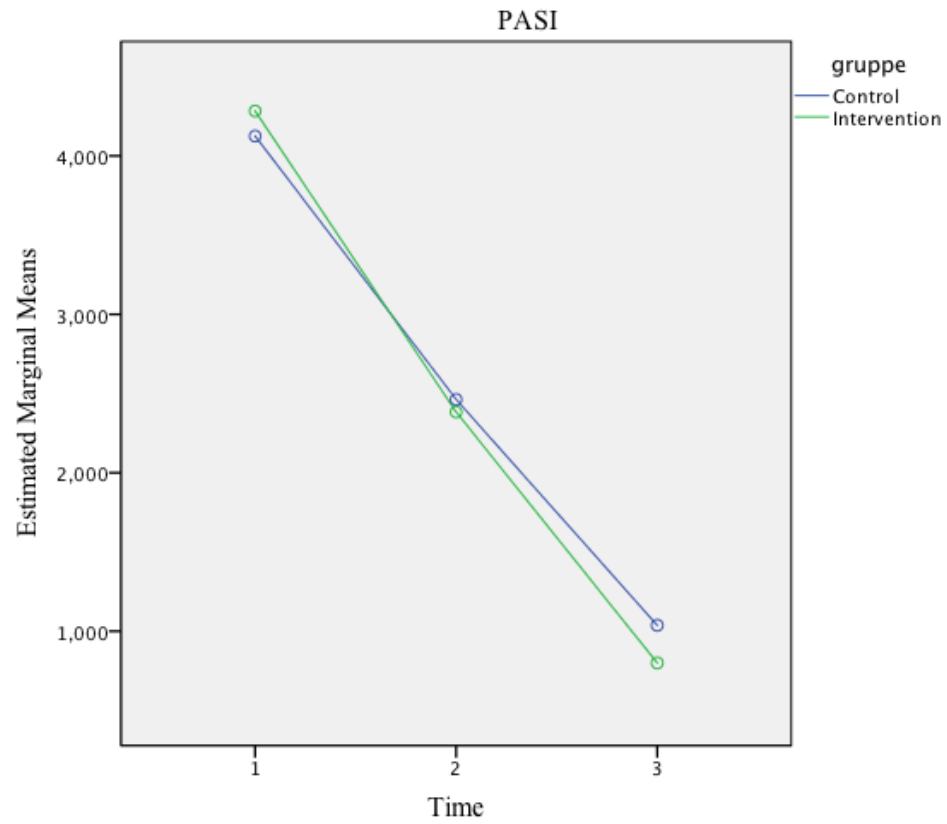


Figure 2. PASI Plot with Mixed ANOVA repeated measures for intervention and control over time.

Mindfulness(FFMQ-SF)

The time practicing mindfulness in hours ($M= 8.25$, $SD=3.4$ $Min= 3.08$, $Max= 13.20$) were satisfactory with an average of 12 minutes each day. The patients performed most frequently the body-scan and sitting meditation. The baseline measures of Mindfulness(FFMQ-SF) was not significantly different between the control and the intervention group on any of the five Mindfulness measures. The difference between baseline and follow-up was non-significant for the five Mindfulness measures. See Table 2. The inter-item-reliability at baseline was acceptable. The low number of participants should lead to caution in analyzing these results. See Table 3.

Stress(PSS), Life Quality(DLQI)

DLQI and PSS was significantly different on Follow-up compared to baseline for the intervention and control group. There was no significant difference among the groups at either baseline or follow-up. The control group had a slightly higher baseline for PSS, but not significant. Results should be analyzed with caution. See table 2.

Clinical assessment(PASI)

The intervention group PASI was at T0 ($M = 5.65$, $SD = 3.13$), T1($M = 2.28$, $SD= 1.44$), T2 ($M = 0.85$, $SD = 0.6$). The control group PASI resulted in T0 ($M = 4.12$, $SD = 2.21$), T1 ($M = 2.5$, $SD = 1.7$), T2($M = 1$, $SD = 0.6$).

PASI was nonsignificant in terms of the differences between intervention and the control ($F(1) = 0.00$, $p = .943$, $\eta^2 = .0$). The light therapy had a significant difference on PASI ($F(1) = 48.72$, $p = .001$, $\eta^2 = .80$) for both groups. The plot describes the overall effect of light therapy with the reduction of PASI. The tests of assumptions were made with Levenes test of variance, Mauchly's Test of Sphericity, and test of homogeneity. None of the test assumptions were violated. See figure 2.

Quantitative summary. There were none of the variables (FFMQ-SF, PSS, DLQI, PASI) that were significant different at baseline or follow-up between the intervention and control group. PSS and DLQI had a significant difference between baseline and follow-up for both intervention and control and the statistical data support that the effect is due to light therapy. The mindfulness measures had satisfactory inter-item reliability.

Qualitative data

The informants were given a pseudonym (Anne, Sara, Frank, Kaja, and Ellen) to protect their identity. Commentary from patients were given single letters (N,Z,K, and S) to protect their gender as well as identity. Several gave rich stories of their illness and their life in general. They often compared themselves to others with psoriasis who had it worse. The chronic aspect was accepted and referred to words like “chronic” or saying, “live with it.” Anne, Ellen, and Kaja said in their statements of having guttate (small spots of psoriasis) psoriasis and shared their troubles using medical creams like cortisone. The small areas of spots are hard to find after treatment and this may increase the risk of treating healthy skin.

The analysis resulted in the final categories: Distress, Life quality, light therapy and Mindfulness, with respective subcategories. The subcategories for Distress were Life events, Aggravating, and Coping. Subcategories for Life quality were Social environment, Discomfort, Area of Disease. Subcategories for Light therapy were adherence, Outcome. Mindfulness subcategories were well-being, Motivation and issues. See table 5.

Table 4. Qualitative table with Categories and sub-categories

Distress	Life quality	Light therapy	Mindfulness
Life event	Social interactions	Adherence	Well-being
Aggravating	Discomfort	Outcome	Motivation
Coping	Area of disease		Issues

Distress

Sara: “Stress influence psoriasis. (...) So that... in stressful periods it flourish”. Most informants presented stress as Sara did here. The belief that stress “influence” psoriasis with adverse effects. In addition, the informants elaborated specific life events regarding their distress and disease.

life event. This sub-category is based on statements from Frank, Anne and Sara. During talk about past incidence, they presented a link between a stressed life event and the onset of psoriasis. The events varied in content, however the common understanding of that stressed situations triggered the disease:

Sara: But I can the tell why Psoriasis broke out (...). I had always , for many years a circular spot on an ankle as a crowned piece. For many years. There was a time that I hurt myself and scrubbed myself, while I was in (on vacation in a warm climate. And it became a dry spot. It stayed there all the time. And then I got a daughter. And when she was one year old, she had fever cramp. (...). She had spasms just like epileptic seizure a. It looks really bad. And she was very bothered by this. And when it is like that and it's a huge stress moment. (...) To avoid her getting these cramps, you need to keep her out so she stays cool. Out and cold. (...) And it was huge stress. No one else could take care of her. (...) When she was young, she had this fever every other day for about three years or so. And this triggered my psoriasis. It spread out on my foot and my elbows.

Sara mentioned a physical damage to the skin and the distress of having a sick child. The child had a disease, which gave frequent seizures. She had to be constant alert, whenever the seizures could occur, which she mentioned as “a huge stress moment”. Sara explicitly related this as an “psychological relapse”, where her “resistance” was weakened as cause of this life event:

Frank: I was very good the first few months after, after the divorce, but they came these, these periods afterwards. Then, suddenly you felt the itching on these areas, and then it

blossomed up. But just in the first period after the divorce, the psoriasis did in fact disappear from the elbow ...the arms, and you thought that was when you were going to have the worst. But the thing is, you feel the outbreaks after a while when you realize more what's going on.

Frank experienced a divorce, but he explained that he didn't have any symptoms of psoriasis in the recent period after the divorce. He had been expecting that it would be at "its worst" just after the divorce, but the symptoms were gone. Then some months later the disease came back. He suggested that the flare-ups perhaps happened when he realized what had occurred. He maintained a belief that distress aggravates the disease.

Aggravate. This sub-category is based on the statements from Anne, Sara, Frank and Kaja. Anne had a distinct experience of working as a middle work manager. She explains the massive work load as well as its effect on psoriasis. She avoided situations with stress, since it aggravated her disease:

Anne: One of those middle manager positions. (...) It was an insane job. And then I thought that I can't do this. Also, considering that it could be worse. That I have to put myself in a situation where eh, yes, not trigger it that much. And, at the same time, in this stressing job, I thought that I can endure this, since the psoriasis is not getting any worse. Because it has generally been an indicator that there's some stress before exams or yes (...) Where I could measure the stress that was good for me because it did not trigger, and the stress that was bad for me because it triggered it (the psoriasis).

Anne experienced the position as middle manager as stressful. She expected the job to aggravate her disease, since her psoriasis had been worse in other stressful situations. Certain kind of stressors triggered her disease and some didn't. In that sense, she could reduce the risk of triggering the psoriasis by avoiding specific stress situations. Similarly, Kaja explained the stress she experienced in her employment:

Kaja: I had first worked for 3 weeks to start with her, and so was the 3 weeks to end this again. And ... I stressed out some insane with it, I wrote and wrote and wrote and wrote

letters (smiles easily), and things changed along the way. (...) Then I saw the almost from every day that the psoriasis spread. It was really a strain.

Kaja elaborated about her one of her work experiences. Based on information from her employer she had decided to change work from public to a private operator. The “oral agreement” was that the job description would be the same, even with the change to a private operator. However, she told that her superior did not keep his/her word on this. The resulting change in circumstances and work tasks was highly stressful for her.

Difficult circumstances may occur in daily life as it did for Frank. An example of such a situation is buying a house, which has legal and economic burdens. He experienced having flare-ups after the dealings with this and he related it to the pressure of the situation. Such a situation may be an extra burden along with life in general:

Frank : You really notice that stress, that it blossoms with stress. (...) When you've been struggling with buying a house (...). That you get such a pressure on you. I really don't know if it's stress (...) You have more pressure on you because you must reply to letters and there are deadlines. And some of the tasks may be difficult. So, I do not feel stressed, but then I feel that it starts to break out because it starts itching in the skin areas where the psoriasis has been.

Coping. This subcategory was based on the statements of Anne, Sara, Kaja, Frank and Ellen. The responses to coping varied among the informants. Ellen, Anne, and Frank were familiar with stress reduction methods:

Anne : Yes. I have done a lot of yoga and it certainly feels like a stress reducer. So, I make use of it frequently, not necessarily the yoga practices, but also just the breathing. Because I have experienced with the job that if I do yoga before a performance, then I have sort of calmed my nerves a little. I also use it more generally. And I miss it. Because when I was a professional dancer we did it all the time and you work a lot with breathing in the dance. So, I was mentally much calmer when I worked with it. Than I can manage to do now.

Whenever Anne was in a stressful situation, she applied a breathing exercise. The practice was based on her experience from doing Yoga, and the sense of being more “mentally calm whenever she performed Yoga. She related her well-being to the times when she practiced more Yoga. Some focused on the coping after the occurrence of stress as Ellen did here:

Ellen: I do (I can handle it), I notice when it is "enough", (I have) a lot of experience. If I notice that it gets too much, then I try to get back in. Maybe try to take me some days off, a little off from work .. yes. Also at home I take it a little more easy, do not participate in that much. It also helps to be outdoors. Go for a walk, I do that every day. I'm trying to collect myself again, by slowing down, take it easy. Do things that I find more fun (to do). Read and...things that I like to do but I really do not get time to do. Ellen referred to her stress as a general load in her life. She mastered the load, by taking some time off from work, going for walks, and doing fun things which she usually lacks the time to do.

The coping of stress was a real challenge for Kaja. She expressed a general worry about being stressed. The discomfort of stress may become an additional stressor for her. She mentioned the need for more time than normal in completing assignments, and therefore the hindrance of time limits and stress. The general feeling of not being able to make it to work by a specific time is something she experienced as a hindrance in life and that creates clear distress:

Kaja: Rather bad. No I have always been late in working, all the time since elementary school. Why, I do not know, but I have always needed to spend more time to do the same task as others. (...) While I also do not have a job that I normally have to meet up at, then I become worried that I won't be able to get there in time or able to get things done when, when there is something.

Distress summarized. The informants urged the importance of acknowledging stress as an aggravating factor to their disease. Indications of worsening in symptoms was often related to their experience with stress. The situations of stress varied between work, everyday life, or disease in family. The informants gave indications that these stressors were long-lasting.

Their application of coping mechanisms was not mentioned in the description of stressful situations. The coping of stressors was explained in a mixture of prevention, calming down, and using Yoga practices. The coping of stress was generally expressed as good, though some informants had clear challenges in dealing with stress. The knowledge of stress reduction methods was familiar for some informants, though the word “stress reduction intervention” may not be well known in the public. The acknowledgement of the distress impact on psoriasis should lead to actions for reducing stress such as stress reduction methods. Stress reduction methods can lower levels of stress and therefore prevent stress from further aggravating the symptoms.

Life Quality

The informants didn't apply the word life quality to a large degree, though the researcher interpreted their statements to be about life quality. Their life quality seemed to vary regarding level of discomfort, the area of disease and social interactions. Many informants claimed that their long experience with psoriasis made them less affected in terms of reduced life quality.

Area of disease. This sub-category is based on statements from all informants. They talked about the difference of having psoriasis in the face and other visible areas: *Anne: Yes, it was during junior high school and I got it in the face (...). So, I think it was a bit horrible.*

Some informants mentioned that having psoriasis in the face was particularly difficult, and Anne describes it as an “horrible” experience. There seemed to be a mutual understanding that the worst places to have psoriasis was in the face, on the hands or other visible areas:

Frank: That you see someone else who has it up in his face. So, I have the trifles in a way. Actually, that I have (it in) those areas. It's not visible in that sense. Many people have it visible on their hands and become sore on the hands and feet.

By comparing his own case to those he considered worse, Frank began to think that his disease was less of an issue in his life. From his perspective, at least he wasn't affected in

areas of the body that are visible to the public. By learning how the informants describe other with psoriasis, we may get a deeper understanding of how they perceive their own disease. Another way to understand illness perception is through how they reflect on their behavior and social interactions social environments.

Social interactions. In different social settings, the symptoms may be visible. Most of the informants cared if the symptoms could be seen, though some did not mind if others saw their symptoms:

Frank: You feel maybe that others look at it and hide it more with clothing with long arms. (...) You feel perhaps more well when all is gone. If you are going to be completely honest with it. Especially in the summer. Now it is winter so you go better dressed. It is about if you dare to admit it, but you feel a lot better.

The sense of “others” watching, made Frank hide his symptoms. An underlying embarrassment could be the reason for concealing symptoms. There is a clear indication of differences in life quality. Most informants relate improved life quality with no symptoms. Frank reflected further on why he hides his disease:

Frank: Doing it for a reason. So maybe it is unconsciously, conscious in a way. You get so used to it that (...). Then I had this thought about why am I so stupid? To hide it away. (...). It's just a regular skin disease

The reason for hiding the disease may lie in the question itself with a combination of habit and unconscious processes. The contrast which creates the question is the contrast of behavior to the perception of “regular skin disease”. The interesting thing is that all of this kind of thinking disappears, when there are no symptoms, as Anne said here:

Anne: And I notice that during summer when there is less and I feel more free with the hair behind the (...). I notice that I do not think of what I wear, as I tend to do a little otherwise. In

what setting I am going to be in, is there a spot under my arm (...). So, a bit like feeling more free when it is better.

Many pointed out as Anne that the disease has often improved in the summer and therefore there is likely a rise in life quality. There is a “freedom” in choosing what to wear and not having to hide in any way. Adaptation is no longer needed, and perceptions of others disappears along with the symptoms.

Discomfort. All the informants had a discomfort in living with the disease. The degree of discomfort varied in terms of symptoms. Most of the informants presented a disappointment when the relapses occurred in the autumn, like Ellen:

*Ellen: This autumn, I think it was (...) I didn't notice it that much, but **suddenly**, it came. It happened very quickly. I don't like that, it was uncomfortable especially when it is cold. Then it becomes dry, and it itches, a then.. yes. And I also found it ugly, red and... When I saw that, I thought that I had to get treatment for it, before it manifested.*

The informants found cold climate to worsen their symptoms and increase discomfort. They also described the development from only having dry skin, to itching and a redness and perhaps becoming “ugly”. Ellen elaborated what she meant with “manifest”:

Ellen: I do not know if it would become like that, but before it becomes thick crusts and scales, that's what I am thinking on; that it develops, but it will certainly not happen. It must not become thick crust and such. It cannot be thick skin, for the light to work. Have you seen ugly cases? Then there are such scales, it becomes thick skin.

Thick crust and scales makes an important difference in discomfort for Ellen as well as most of the other informants. She also argues also that the light therapy requires no thick skin for the best effect. The discomfort increases when the severity increases to the stage with thick crust and scales.

Life quality summarized. The life quality improved in the summer and after treatment, though it worsened during relapse. Certain areas like hands and face were considered as more visual for others to see, and the degree of discomfort was also greater when the skin was affected in those areas. In social settings, they felt uncomfortable when symptoms were visible, and therefore made efforts hiding it with clothes, such as wearing long sleeves. The behavior of hiding the symptoms during relapse may indicate an embarrassment and perhaps also a disappointment that the disease returned. Whenever the symptoms were gone, the behavior of hiding the skin vanished in thin air. A relapse with more severe symptoms seemed to lower their life quality. A relapse was also assumed to potentially develop into more permanent and manifest symptoms of the disease, with areas of thick and scaled skin, and this seemed to raise concerns of future disease progression.

Light therapy

All informants performed light therapy and most of them were interviewed when they attended their final treatment session. Some of them had received light therapy previously, often many years ago:

Anne: *“So, it is several years since (previous light therapy treatment). I consult my doctor only when I think it is a total crisis. So, I live with spots here and there, all the time.*

Adherence. This subcategory is based on statements from Anne, Sara, Frank and Kaja. Most of the informants had not completed light therapy in several years, and some had relapses during this period. Among the informants there seemed to be an acceptance of living with the “constant” disease. Anne elaborated that it had to be a “crisis” before she went to the doctor. The informants in general presented a high threshold to seek treatment. The exact reason for treatment varied, but the common description was a fast-adverse development of disease. This was how Frank described it:

Frank: well, it may go for a while, and like the dots suddenly disappeared, perhaps for a month, and then they came up again. And now when it was at the worst, I had small-dots

up through, up the arms and a little on the chest, and when you were in the shower, then after a shower you were red-dotted up on the leg. It was like the skin, when it was wet you could see indications that the psoriasis was going to break out. Because now and then I had like small white scales that came loose and then I went to the doctor and had the light treatment. (...)I didn't worry anything more about it. I just noted that "Oh, I have had a lot more (now)".

Frank saw the signs of the disease in terms of red spots and scaling. The Relapse was acknowledged by Frank and then he attended light therapy. He accepted the fact that he has a chronic disease, though he realized that the disease progressed. As Ellen previously mentioned, “scale# and “thick skin” can minimize the effects of light therapy. This is an important argument for seeking early treatment in preventing a manifestation of the disease. They underline the importance that they do not worry about how the disease progresses, though they mention the undesired areas of the disease, and how their illness is compared to more worse cases. A general concern was their thoughts about disease progression.

Light therapy was described as time consuming, related mostly to the transportation to the hospital. This varied in terms of proximity to hospital as Sara mention here:

Sara: No, it doesn't matter. And the reason for that is that I'm 2 minutes from the hospital. So, you can imagine if I had stayed in the city center and that I had to drive and not have parked. Then I had spent two hours on it. Instead of that I use the 7 minutes it takes.

When living as close to the hospital as Sara does, time is less of an issue, especially since light therapy only takes a few minutes. The difference was as Sara points out that the time drastically increases, when living 20-30 minutes away. With traveling, back and forth this could take as much as 2 hours. In her case this was no real issue. For others, the time consumption was a factor in their adherence for doing light therapy:

Anne: When it is, nearby I take it more. Like that with the Sun. In Bergen, I had only 2 minutes walk to the sun treatment so then I did it a little more often. But for a six-week period, but perhaps two weeks prior to a performance. So, I could go on a regular basis without that there was any hassle. But when it is like far away. (...) Then I won't do it. Only

if it is a crisis, I would bother to go. Ehhm. So now (...). Yes, I came quickly to treatment when I asked the doctor. Also, I had time to go to the hospital 3 times a week (snapping with fingers these 6 weeks. So, I did that. But I think it have to be quite serious for me to make the efforts again. That close to the treatment (facility). To the Sun (treatment). Since this is what helps me the most. It is certainly an indicator that I would make the effort.

Anne presented her “indicator” that she would do light therapy. In her statement proximity to treatment was a crucial point. Short distances to treatment reduced the threshold for seeking and adhere to treatment. Long distances as in the present situation, makes a “hassle” since it requires more time in traveling between home and the treatment facility. Anne seemed to perceive 6 weeks of 3 sessions per week as quite a lot. She specified that light therapy was the best treatment for her and that leads us to the outcome of light therapy.

Outcome. This sub-category is based on all informants with the importance of the outcome of treatment. Most of the patients were satisfied with the treatment and particularly those (Anne, Kaja, Ellen) with spot/guttate psoriasis (guttate psoriasis):

Ellen: The light treatment was perfect, but of course there is a danger of using too much sun. Twenty treatments over six weeks ' time. But I was thinking about (the risk for) moles, and skin cancer, yes. Limited use does not have any high risk for that, one might say.

Most of informants had a positive satisfaction with the treatment and one mentioned the risk of light therapy for skin cancer. The risk is perceived as low, since the “limited use” do not present any significant risk of cancer. Some informants were disappointed when the disease came back after the treatment:

Frank: This is the third time I have light treatment during these years. I remember especially the first time I came in and then everything disappeared, and then it reappeared. That this was a disappointment, I have to admit. Because, you believe you are going to be perfect. You can't be perfect, really. But true. You get it back. Hell, it appeared again and that's a disappointment. Because I would lie if I said it wasn't.

It is important to note that Frank's expectations for getting the disease back was in terms of stress rather than only related to light therapy: *Frank* : “So I expect that given the hassle I have today with the House, it will come back and maybe a little faster.”

In the context that Frank had 3 periods of light therapy during a decade of having psoriasis, he expressed that there is a “disappointment” when the disease “reappeared”. The accepting of such a short-lasting effect, may reduce the adherence for light therapy.

Light therapy summarized. Most patients had not been to light therapy in many years, even though some of them had the best effect from this treatment. The reason for seeking treatment was often that the disease had the potential to become more severe, though the threshold for seeking treatment was quite high. Time perspective is an important factor for some if they attend the light therapy. The most time consuming was not the treatment, but transportation to treatment. If a patient uses 1 hour back and forth between treatment, then it adds up to a total of 18 hours in 6 weeks only in traveling. In comparison with 2 minutes each way, it is approximately 4.2 hours. The outcome was satisfactory for the informants, although it was only temporary, and some were disappointed that the symptoms reappeared a while after.

Mindfulness

Three of the informants (Ellen, Sara, and Frank) were in the intervention group. Four other intervention patients gave comments about the mindfulness intervention. They experienced the effect of the intervention quite individually, but with some similarities. Frank and Ellen had some experience in doing relaxation techniques, but for Sara this was a completely new practice:

Ellen : I have been to yoga, so it was not entirely unknown to me. But it's probably a couple of years since I attended a course, but then she (the instructor) moved, and I sort of fell out of it. And (I) haven't started with it after that. That's perhaps why I said "Yes" to this. I really enjoyed it. It's also this with meditation.

Like Anne, Ellen compared her previous Yoga experience with mindfulness. Her experience in doing meditation was the reason for signing up on this study.

Well-being. Sara mentioned one of the most frequent effect from the intervention. *Sara: "It's a nice thing to use to calm down. And especially if it is stress. Manage to bring you in."*

The intervention was in her words a "nice" way to "calm down", and especially during times of stress. In the sense of reducing stress, Frank was in the situation of buying a house, which created even more stress and pressure. He described his experience with mindfulness during this stressful period like this:

Frank: That there are many problems and stuff like that the little things so I have used to have said that when it was has been like that so I have used to say that "now I'll go to listen to the audio file, now I have to drop some problems". It can be a joke, but sometimes it can be serious. But I think it was the most important. But if you think consistently so I have been gotten away and really clear and drop it in a good period yes maybe. The House took part, but I know that I've ever clear in two days where I do not plan on the House and all the time ready to steer away from certain thoughts and drop them quickly. So, it has been incredibly good. It has enough helped me a bit in mindset of how one think.

The well-being Frank felt when doing mindfulness was a sense of reduced stress in letting go of daily "hassles", things that really did not matter in the bigger picture. Somethings may be more serious as his house buy, which he didn't think about for short periods. He relates the present situation after this period:

Frank : I felt itch Friday after the inspection and I knew that it itched on the areas where I have psoriasis. So right now, I feel awesome with myself. You feel the audio track and the thoughts you have experienced in the period. So, you get the feeling that you have coped with it. And coping is positive.

He used the word "audio track" whenever he talked about mindfulness. After his treatment period, he felt a small flare-up. He argues the importance of mastery during this

treatment period as a link to practicing mindfulness. Frank`s experience seems to have brought him a better sense of well-being and calmness. He had a certain consciousness about own emotions and thoughts which was similarly mentioned in a commentary: Z:” *Was very conscious of my emotions and body when I listened to the audio file and very relaxed.*”

In the contrary to all other informants Ellen had a different experience of the intervention:

Ellen: But it had I also when I held on with yoga. Then I thought that I had better sleep quality. Woke up not at night, I sleep better. If it's just in my head or ... I don't know. But it was an experience I had at least. The same experience I had. It's also the way that by large load and also stress, so one can in a way get poorer sleep. Wake up in the night and start thinking about ... work tasks, things you'd done and so you can't sleep. So. .. It seemed to me ... the experience I had.

She experienced stress from work and it affected her quality of sleep, as it had done in earlier occasions. The former practice with Yoga had resulted in better sleep, which she also mentioned here with relation to mindfulness. Ellen described the practices more in detail and also the context of light therapy:

Ellen: Yes, I enjoyed them! Mmm. Now it was not every day and I didn't do everything.. But what I liked the most was this body the transition, with the sitting meditation. That I liked the best. It happened that I ran through all the. So, they are I enough to use on; practically. (...)Yes. What I did at the end when I was longer in the light box, so I tried to run through a body transition inside the light box, had the focus on bone and add and knees. Yes, for when you are sitting for a while and at the end so I put/stood there in 6.7, 8 minutes. So, at the beginning of 1 minute did I somehow think, did not come far at least (smiles easily). You get as far as breathed in.

Ellen had benefitted from the mindfulness practice and she appreciated mostly the body scan and sitting meditation. She did some practice inside the light box, when the time of the treatment reached “6,7, 8 minutes”. She mentioned briefly at the end “I will use

mindfulness to prevent my next relapse”. Her belief in doing mindfulness for its benefit of better sleep.

Motivation. Two informants (Sara and Frank) practiced mindfulness in a room close to the skin clinic. The motivation was illustrated in term of how much they practiced, but also the use after the study:

Frank: *I heard a lot in the beginning. And it was I think was very good. (...) But I think I've been dropping by the Mindfulness now in every week after I have stopped on treatment.*

Most of the informants were motivated to doing mindfulness, and some even practiced after the treatment such as Frank and Ellen. Some patients had different experiences of doing mindfulness than the informants presented:

N: I did not become any healthier. I do not see the use of philosophy about life.

The motivation here was mostly linked to the result, and when the result was not as expected it is only logical that the spirit faded away.

Issues. There were some issues with the mindfulness practice. The overall issues were presented by Ellen and a commentary: S: *the sound files are for a time very monotonous. Personally, I have had problems with not to fall asleep by. It will say that I think it's just a couple of times that it did not happened.*

As it states the intervention was perceived to be bit to “monotonous”, which was presented also by Ellen that she sometimes became sleepy while listening to the intervention. Sara was quite new to the experience of doing mindfulness and had a different angle to the mindfulness:

Sara: *I don't know if you can learn them after having been listening to the mindfulness. And learn how to calm down. But it's a learning it as well. So, you got to use it a long time, I think.*

I don't think it's going on 6 weeks. Because I think I have to use half a year to be able to connect all the other thoughts than you have on your ears.

For Sara, there was not enough time to practice in mindfulness, especially since stress reduction was already a new experience for her.

Mindfulness Summarized. Informants and patients had in general a better well-being after doing the mindfulness practice. The sense of well-being differed among the patients, for some it was the sense of being calm, sleeping better, or becoming more conscious about own thoughts and feelings. Some related their experience in doing Yoga with this specific Mindfulness intervention. One practiced inside the light box during their body scan. Overall, motivation to take the time to practice was good and some had clear intentions to keep practicing after the study. Some had issues with being sleepy after doing the intervention. The intervention was a good supplement for light therapy by reducing perceived stress and increasing well-being.

Discussion

The aim of this pilot study was to: To develop a study design for assessing the effect of Mindfulness intervention combined with Ultraviolet Phototherapy(UVB) in patients with moderate- psoriasis.

This pilot study had a significant reduction in perceived stress(PSS), severity (PASI) and improvement of life quality (DLQI) for both groups. There was no significant difference in baseline or follow-up between the intervention and control group for perceived stress, life quality (DLQI), severity (PASI), and the Mindfulness measure (FFMQ-SF). Mindfulness measures in the intervention group showed no significant difference between baseline and follow-up. Light therapy explained the effect size with 80 % between T0-T2 for severity(PASI). There was a non-significant tendency of lower PASI, whenever traveling to warmer climate during the last 3 months. Research has emphasized the importance of controlling for warm climates (Vedhara et al., 2007).

The results do not support our expectations of larger Mindfulness (FFMQ-SF) scores for the intervention group, however the inter-item reliability was satisfactory at baseline. The improvement of life quality and the reduction of perceived stress and PASI was as anticipated. Mindfulness training was pleasing in terms of amount and regularity in training for the patients with approximately 12 minutes each day, which has been reported in earlier home interventions for mindfulness (Vettese et al., 2009). The design may well be suited for a bigger study, especially since the instruments behave as we expected. Results should be analyzed with caution due to low number of participants.

Distress

The informants acknowledged stress an aggravating factor for their disease, similarly to what another qualitative study had found (Bundy et al., 2014) . The stressful situations that were described were often related to work, everyday life, or disease in the family. These situations were repeatedly long-lasting and with no clear way of removing the stressor. (Bundy et al., 2014) .

The interesting thing is that they didn't mention their sense of coping in situations which they had perceived as more stressful than others. They issued the consequences of being in those situations over time. Some claimed that those consequences were the onset of disease and the flare-ups of psoriasis. In the belief of these circumstances, the coping of stress may well reduce the risk of worsening the disease. The problem-focused approach is not sufficient, when the stressor cannot be altered, such as the examples of disease in family, and divorce brought up by the informants. The interesting thing is that some informants didn't mention their sense of coping in the stressful situations. That may indicate they did not applied emotional-coping under the circumstances.

Some informants mentioned breathing techniques, and meditation with Yoga. These two methods may be an emotional-focused coping, where the target is not the stressor, but the physiological arousal of the stressor. The reduction of the response provided a sense of calmness, even in the presence of stress. By application of these ways of coping, you deal

with the stressor without altering it. Mindfulness may be emotional-focused coping, since it changes the relation to the stressor and in that process, it calms and reduces the stress. Acknowledging how distress impact this disease should lead to use of practical stress reduction methods such as Mindfulness to prevent further stress aggravation.

Mindfulness

The performance of Mindfulness lead to better subjective well-being which was experienced as a sense of calm, increased quality of sleep and increased awareness of own thoughts and feelings. The psychological well-being is a commonly reported outcome from practicing Mindfulness (Keng et al., 2011). For some, Mindfulness has become a method to cope with daily life. Through the ability to become more in touch with one's emotions and thoughts, it can be easier to learn to release them and not feel overwhelmed by daily hassles. It can create a sense of relief when you detach from own thoughts and feelings, and perhaps begin to choose more wisely what to react to and what to let go of. Self-control in challenging or stressful environments, can be crucial for the present busy population in western society. Mindfulness could be an emotional-focused coping in the sense of Lazarus and Folkman model(1984), which rather focus on reducing the physical response by the relation to the stressor, rather than trying to alter the stressor . Improved sleep quality is often reported in Mindfulness intervention studies (Goyal, Singh, Sibinga, & et al., 2014). Mindfulness have different effects for individuals for psoriasis , which another qualitative study underlines (B. A. Fordham, Nelson, Griffiths, & Bundy, 2015) The outcomes of mindfulness may differ, and also the expectations based on their experience with stress reductions methods. The patients who had former experience with Yoga, and stress reduction practiced more frequently and increased subjective well-being. Former experience with stress reduction interventions may have more accurate expectations on what mindfulness could contribute. Some patients didn't see the purpose of the intervention, as it did not improve their psoriasis. The intervention is not suited for all with psoriasis as the individual preference differs (Hunter et al., 2013).

Life Quality

The quality of life varied in terms of the different seasons. During the summer, life quality was described as having improved, while in the winter was more likely to end in relapse. The disease had a relatively big impact on their life at baseline with approximately DLQI= 10, where $DLQI \geq 11$ is assumed to be a boundary where topical treatments are not sufficient (Finlay & Khan, 1994). Most informants argued for the big impact the current relapse had on life quality, while others had clear discomfort with their disease, but did not report it as lowering their life quality. One informant had particularly high discomfort with itching on the hands, but only reported $DLQI < 6$. DLQI has one direct question about itching, and the others are indirectly connected to the consequences of the skin disease in behavior from oneself and others. The degree of itching and its impact on the life of psoriasis may be an important aspect to influencing the life quality of psoriasis patients. The VAAS questionnaire has been suggested as good instrument for detecting itch impact on the life of those with psoriasis (Globe, Bayliss, & Harrison, 2009; Prignano, Ricceri, Pescitelli, & Lotti, 2009).

The stigma or embarrassment of having visible symptoms seems to have led to the use of clothes as a means to hide psoriasis, for instance by wearing long sleeves whenever going to the store. (Ghorbanibirgani, Fallahi-Khoshknab, Zarea, & Abedi, 2016). The discomfort was often greater when symptoms were in visible areas, such as the face and hands. The choice of hiding the skin symptoms in public may well be a habit, as well as some unconscious processes. The life quality measure of DLQI has multiple questions for detecting discomfort of socially interacting in society, though it did not pursue the subjective meaning as with conducting interviews.

The discomfort increased with presence of thick skin, scales and crust, which is suggested by the informants and former research as manifestation of the disease (Prignano et al., 2009). The informants mentioned their concerns about future disease progression. They often compared themselves to worse cases of psoriasis, such as having it on the face, hands, or having thick skin, crust, itching and scaling. The understanding of how psoriasis patients

look upon worse cases and their own behavior in social settings may increase knowledge about how they perceive their life quality.

Light therapy

The informants had not been to light therapy in many years, even though some of them had experienced the best effect from this specific treatment. The informants seemed to attend their treatment when the disease began to develop quickly and adversely. The concern about manifestation and increased discomfort seemed to be the trigger for approaching treatment. The adherence for performing light therapy appears to be an important theme along with the relevance of time and distance from home to the hospital clinic (Kalia et al., 2014). Traveling to and from the light therapy is what is most time consuming, given that the treatment itself can be as short as seconds to a few minutes. Take a moment to consider two patients, one has 2 minutes to the treatment and the other 30 minutes. The difference is not huge in one single treatment, however it is substantial over six-weeks with three sessions a week. The time consumption is 18 hours for the first one and only 4,2 hours for second one, and that makes distance relevant in terms of adherence. It is clearly more disruptive in to spend 18 hours compared to 4,2 hours traveling to treatment.

The patients had good outcomes from the treatment in terms of significant reduction of PASI, DLQI, and the informants had good subjective satisfaction. Informants with Guttate psoriasis appeared most pleased with the light therapy (Fernandez-Guarino et al., 2017). The effect of the treatment was for some informants short lasting. The reappearance of symptoms for some informants was disappointing and may reduce their adherence for light therapy in the future.

Strengths and limitations

This pilot study demonstrates how Mindfulness combined with light therapy in design can show measured benefits of increased subjective well-being, however there are some limitations. A major limitation is the low number of participants with N=16, which should

lead to caution when reading results. A power analysis would give indications of how many participants are needed for a larger study.

The quantitative data are reliable and valid, though they are mostly self-report except for PASI. PASI is one of the major strengths with three measures for each patient and respected as the most reliable and valid assessment for measuring the severity of psoriasis (Cabrera et al., 2015). In intervention studies the control group is an important aspect for detecting the difference as we did with Mindfulness in adjunct to light therapy. The registration of practice during mindfulness is an advantage, which is recommended for home interventions (Vettese et al., 2009). The short introduction to mindfulness as a practice and concept proved to be shortcoming in terms of giving accurate expectations of what the intervention could contribute. The qualitative data provides extensive insight in how patients perceive their mindfulness practice, own disease, and treatment.

Future directions and contributions

This study contributes to methods of measuring mindfulness in a medical setting, as well as increased understanding of patients experiences with their disease and treatment. Our findings have a clear clinical relevance for patients experiences in light treatment and reported troubles using cortisone for guttate psoriasis. There is a need for more research in supplementing mindfulness to psoriasis populations.

A larger study should include informational meetings with a mindfulness instructor, which is common for MBSR (Mindfulness based stress reduction) and MBCT(Mindfulness based Cognitive Therapy) (Fjorback et al., 2011). The meeting would ensure meaningful and realistic expectations about the process in practicing Mindfulness. Qualitative studies with IPA could give a deeper understanding of psoriasis as a disease and concerning the adherence of treatment. The practice during mindfulness intervention should be logged for relating effort and effect, especially since time and frequency in training mindfulness could differ more than MBSR and MBCT (Vettese et al., 2009).

Conclusion

Mindfulness can easily be combined with Light therapy(NB-UVB) as a supplement. The intervention increased subjective well-being among informants and patients. The acknowledgement of the impact of distress on the disease should lead to practical use of stress reduction methods such as Mindfulness to prevent further stress aggravation. Mindfulness may be an emotional-focused coping which could reduce the physical response, without altering the stressor. Patients had a high threshold for seeking treatment, which was reasoned with it being too time consuming due to the distance to treatment.

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Appendix

- 1 Vedlegg
- 2 Intervjuguide
- 3 Intervjuer: Takk for din deltakelse. Vi tar opp dette på et audio opptak som vil bli slettet etter
- 4 at studien er slutt.
- 5 Intervjuer: Meningen med studien er å se om mindfulness/ oppmerksomhetstrening har en
- 6 effekt på lysbehandling og få en større forståelse av hvordan det er å leve med psoriasis.
- 7 Intervjuet vil omhandle din opplevelse av psoriasis, stress, behandling, og hvordan du selv
- 8 oppfatter din oppmerksomheten i forhold til ytre og indre omgivelser med tanker og følelser.
- 9 Intervjuer: Du lever og har levd med psoriasis i en lengre periode. Hvilke erfaringer har du
- 10 gjort deg i løpet av denne tiden?
- 11 Intervjuer: Beskriv hvordan du oppfatter din kroniske sykdom
- 12
- 13 Intervjuer: Foreligger det noe usikkerhet med å leve med psoriasis?
- 14
- 15 Intervjuer: Tenker du mye på hvordan nye sykdomsperioder vil bli?
- 16
- 17 Intervjuer: Forbereder du deg til vintersesongen i forhold til huden og mulig forverring? På
- 18 hvilken måte?
- 19
- 20 Intervjuer: Hvordan forholder du deg til andres oppfatning av din sykdom?
- 21
- 22 Intervjuer: Hvordan oppleves det når sykdommen blir visuell for deg selv og andre?
- 23
- 24 Intervjuer: Hvordan er opplevelsen av tilbakefall?
- 25
- 26 Intervjuer: Hvordan vil du beskrive konsekvensene av tilbakefall på det livet går i nå?
- 27
- 28
- 29 Intervjuer: Hvordan er prosessen av bedring?
- 30
- 31 Intervjuer: Hva betyr bedring for din hverdag?
- 32
- 33 Intervjuer: Hvilke erfaringer relaterer du til livskvalitet og din egen sykdom?
- 34

- 1 Intervjuer: Hvordan opplever du stress?
- 2
- 3 Intervjuer: Hvordan takler/løser du stress?
- 4
- 5 Intervjuer: Kan du beskrive din opplevelse av lysbehandling?
- 6
- 7 Intervjuer: Kan du fortelle om dine erfaringer tilknyttet daglig behandling?
- 8
- 9
- 10 Intervjuer: Fortell om dine erfaringer med bruk av ulike behandlinger?
- 11
- 12 Intervjuer: Hva er din opplevelse med nåværende behandling?
- 13
- 14 Intervjuer: Har du deltatt eller har du kjennskap til stress reduksjons metoder?
- 15
- 16 Intervjuer: Hva er ditt inntrykk og opplevelse av mindfulness?
- 17
- 18 Intervjuer: Opplever du at du er oppmerksom på lyder som klokke tikking, eller biler som
- 19 kjører forbi? Hvordan lukt?
- 20 Intervjuer: Vurderer du om dine tanker omliggende psoriasis er gode eller dårlige? På hvilken
- 21 måte? Fortell litt mer.
- 22
- 23 Intervjuer: opplever du at du gjør ting uten å være oppmerksom? Kan du fortelle litt mer?
- 24
- 25 Intervjuer: Føler du at du er god til å legge ord på dine følelser? Kan du beskrive litt mer?
- 26
- 27 Intervjuer: Finner du det vanskelig å være fokusert på det som skjer nåtiden?
- 28
- 29 Intervjuer: Setter du ord på ting selv når du er opprørt?
- 30 Intervjuer: Når det kommer ubehagelige tanker eller følelser, reagerer du eller observerer du
- 31 dem uten å reagere? På hvilken måte?
- 32
- 33 Intervjuer: Prøver du noen ganger å skyve bort dårlige tanker?

1

2 Intervjuer: Fortell gjerne om det er noen uklarheter med spørsmålene gitt fra spørreskjemaet.

3

4 Intervjuer: Hvilke erfaringer har du gjort ved å delta i denne studien?

5

6 Intervjuer: Takk for din deltakelse. Ha en fortsatt fin dag.

Universitetssykehuset Nord-Norge



TAUSHETSERKLÆRING

Tøm skjema

Skriv ut

JEG FORSTÅR:

- At jeg i mitt arbeid/praksis som ved UNN vil kunne få kjennskap til forhold som det av hensyn til pasienter, deres pårørende, barn og foreldre/foresatte eller andre er nødvendig å bevare taushet om.
- at dette arbeidet krever ansvarsfølelse, lojalitet og pliktroskap.

Jeg har satt meg inn i den nedenfor siterte lovbestemmelse.

Jeg er klar over :

- at brudd på taushetsplikten kan medføre straffeansvar og eventuelt fjernelse fra tjenesten.
- at taushetsplikten også gjelder etter at jeg har sluttet i tjenesten

Fødselsdato:

27.11.1990

den 04.04.2017

Erling Hovked
underskrift

Fra "lov om spesialisthelsetjenesten" kap.6

§ 6-1. Taushetsplikt

Enhver som utfører tjeneste eller arbeid for helseinstitusjon som omfattes av denne loven, har taushetsplikt etter forvaltningsloven §§ 13 til 13 e.

Taushetsplikten gjelder også pasientens fødested, fødselsdato, personnummer, statsborgerforhold, sivilstand, yrke, bopel og arbeidssted. Opplysning om en pasients oppholdssted kan likevel gis når det er klart at det ikke vil skade tilliten til helseinstitusjonen. Opplysning om en pasients navn, transportbehov og om pasienten skal betale egenandel og eventuelt belepet kan gis til transportør i forbindelse med transport etter § 2-1a første ledd nr. 6.

Opplysninger til andre forvaltningsorganer etter forvaltningsloven § 13 b nr. 5 og 6 kan bare gis når dette er nødvendig for å bidra til løsning av oppgaver etter denne loven, eller for å forebygge vesentlig fare for liv eller alvorlig skade for noens helse.

PASI - PSORIASIS AREA AND SEVERITY INDEX

Navnelapp:

Dato:

PSORIASIS LESJONENS ALVORLIGHET

0=ingen 1=lett 2=moderat 3=alvorlig 4=veldig alvorlig

Sett sirkel rundt et nummer i hver kategori:

		Hode	Truncus	Overeks.	Undereks.
1	Erythem	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
2	Tykkelse	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
3	Skjelling	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4	0 1 2 3 4
4	Total				

PSORIASIS UTBREDELSESOMRÅDE

5	Grad av involvering	0=ingen 1=< 10 %	2=10-<30% 3=30-<50 %	4=50-<70% 5=70-<90 %	6=90-100 %
6	Sett inn grad av involvering fra rad 5				
7	Multipliser rad 4 med rad 6				
8		X 0.10	X 0.30	X 0.20	X 0.40
9	Multipliser rad 7 med rad 8				

TOTAL PASIScore:..... (Legg sammen hver kolonne i rad 9)

LEGE:



Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord	Lill Martinsen	77646140	05.12.2016	2016/982/REK nord
			Deres dato:	Deres referanse:
			18.11.2016	

Vår referanse må oppgis ved alle henvendelser

Svein Bergvik
Institutt for psykologi

2016/982 Psoriasis og mindfulness> en pilotstudie
Forskningsansvarlig: UiT Norges arktiske universitet
Prosjektleder: Svein Bergvik

Det vises til prosjektendring av 18.11.2016, besvart av REK 23.11.16, hvor det ble bedt om nærmere beskrivelse, samt avmerking av omsøkte endringer i protokoll og informasjon-/samtykkeskriv.

Vi har nå mottatt tilbakemelding med vedlegg, hvor omsøkte endringer er markert i protokoll og samtykkeskriv. Den omsøkte endring gjelder innhenting av ny data fra allerede inkluderte deltakere.

Ny data skal knyttes til en ny problemstilling i studien «Hvilke erfaringer har deltakerne i forhold til å ha psoriasis og relatert til behandling, livskvalitet, tilbakefall av symptomer, endringer og bedring av symptomer, mindfulness og opplevd stress?». Innhenting av ny data skal gjøres i forbindelse med kvalitative intervju med deltakerne som allerede har samtykket til deltakelse, og i nytt revidert informasjon-/samtykkeskjema forespørres deltakerne om intervju i forbindelse med utlevering av siste spørreskjema. Deltakerne har da mulighet for samtykke eller reservasjon til intervjudelen.

Etter fullmakt er det fattet slikt

vedtak

Med hjemmel i helseforskningsloven § 11, godkjennes prosjektendringen.

Sluttmelding og søknad om prosjektendring

Prosjektleder skal sende sluttmelding til REK nord på eget skjema senest (et halvt år etter prosjektslutt), jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK nord dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang

Prosjektleder kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra mottak av dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
Sekretariatsleder