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Norske Kvinners  
Sanitetsforening



STIFTELSEN  
DAM

## SLUTTRAPPORT

# Utvikle Intervensjon for Fibromyalgi

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Søkerorganisasjon: Norske Kvinners Sanitetsforening

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## Forord

Rapporten beskriver et arbeid som forskere, en tverrfaglig klinisk gruppe og leder av en rehabiliteringsenhet i spesialisthelsetjenesten har samarbeidet om. Prosjektet handlet om å utvikle et opplegg for pasientundervisning for pasienter med fibromyalgi på en systematisk måte, deretter prøve ut den nyutviklede intervensjonen i klinisk praksis og evaluere om innholdet erfares meningsfullt og nyttig.

Mange har vært involvert i prosjektet, og det rettes takk til fagpersonene som deltok i utviklingsarbeidet, de som gjennomførte intervensjonen og pasientene som har stilt opp og delt sine erfaringer med andre pasienter, helsepersonell og forskere.

En takk til Revmatismesykehuset A/S, Lillehammer som ga oss mulighet til å utføre arbeidet ved sykehuset. Takk også til Norske Kvinners Sanitetsforening for interesse for søknad og for hva det resulterte i, og ikke minst til Stiftelsen Dam, uten prosjektmidler hadde det ikke vært mulig for oss å gjennomføre dette prosjektet.

## Innholdsfortegnelse:

Sammendrag.....	s. 4
Kap. 1. Bakgrunn for prosjektet.....	s. 5
Kap. 2. Målsetninger og målgruppe.....	s. 5
Kap. 3. Prosjektgjennomføring/metode.....	s. 5-6
Kap.4. Resultater, vurdering av effektmål og resultatvurdering.....	s. 6-7
Kap 5. Oppsummering og videre planer.....	s.7-9
Referanser skriftlig materiale.....	s.9

## Sammendrag

**Bakgrunn:** Fibromyalgi (FM) er en hyppig forekommende kronisk smertetilstand. Diagnosen er omdiskutert, og behandlingstilbudene er mangelfulle og har lite varig effekt.

**Målsetting:** Å utvikle, prøve ut og evaluere utbytte av et nytt pasientundervisningsprogram for pasienter med FM.

**Metoder:** I fem heldagsseminar over en periode på et halvt år ble det reflektert på tvers av fagkunnskap, kliniske erfaringer og forskningslitteratur om pasienters erfaringer med å leve med FM og tilfriskning. Dette arbeidet ble utført på en systematisk måte. To forskere ledet og stilte spørsmål i diskusjoner, analyserte og fortolket diskusjonene i lys av teori i etterkant og presenterte resultatene for gruppen til videre refleksjoner/diskusjoner. Arbeidet resulterte i en skriftlig teoretisk begrunnelse for hvorfor denne intervensjon, dets hensikt og innhold. Pasientundervisningsprogrammet ble så prøvd ut i klinisk praksis og justert etter feedback fra pasienter og helsepersonell. Utbytte ble evaluert i fire grupper bestående i alt av 40 pasienter. Pasientene besvarte spørreskjema knyttet til alvorlighetsgrad av FM før, umiddelbart etter, samt etter 6 og 12 måneder. I tillegg ble 11 pasienter intervjuet individuelt for å undersøke hvordan pasientene hadde tatt i bruk det de hadde lært i tiden etter pasientundervisningen. Helsepersonell (n=8) ble intervjuet om sine erfaringer med å arbeide i programmet.

**Resultater:** Det ble utviklet et personrettet, ressursorientert pasientundervisningsprogram begrunnet i eksisterende forskning hvor hensikten er at pasienten skal arbeide med å utforske sammenheng mellom plager, seg selv og sitt liv for å gjøre situasjonen begripelig og håndterbar. Programmets hensikt og innhold ga mening for pasienter og helsepersonell. Etter et års tid hadde pasientene gjort mange små og større endringer i sitt liv, hadde fått flere gode dager, hadde tro på sin egen evne til å skape ytterligere bedring i fremtida. Helsepersonell erfarte at det hadde blitt mer positivitet i gruppene enn før, følte seg trygge på at det de leverte hadde betydning for pasientene, og utviklet stadig sin egen kompetanse gjennom å reflektere sammen med resten av teamet over hva de erfarte i gruppene.

**Vurdering av prosjektet:** Dette har vært et krevende arbeid som har ført til mye tenkning og refleksjon. At forskere og et tverrfaglig rehabiliteringsteam har samarbeidet om å utvikle en intervensjon, har vært en suksessfaktor og resultert i kunnskap som vi neppe hadde klart å komme fram til uten hverandres ulike kunnskaper og erfaringer. Forskere har bidradd med systematikk, utfordrende spørsmål og skriftlig materiale. Rehabiliteringsteamet har stilt spørsmål ved både sin egen kunnskap og forskernes, og forskerne har arbeidet med å sette «puslebitene» sammen til en helhet ved hjelp av teori. Å utvikle en tydelig forståelse av hvordan vi forstår FM og hvordan dette henger sammen med hva vi gjør i programmet, har vært viktig for pasientene, helsepersonell og forskere. Denne tydeliggjøringen har også gjort det mulig å evaluere om intervensjon har ført til bedret håndtering av utfordringer og mindre plager. De positive erfaringene videreføres og tas nå inn i andre arenaer på sykehuset. Ved Universitetet i Oslo videreføres arbeidet av en postdoktor finansiert av Fysiofondet for spesielt å videreutvikle fysioterapidelen for pasienter med FM i primærhelsetjenesten.

## **Kap 1. Bakgrunn for prosjektet**

Fibromyalgi (FM) er en hyppig forekommende kronisk tilstand som kjennetegnes av generelt utbredte, vedvarende smerter i muskelskjelett, søvnproblem, uttalt tretthet, mageproblem, og depresjon. Plagene varierer på uforståelige og uforutsigbare måter for pasientene og begrenser daglig fungering. FM kan ikke påvises ved blodprøver og røntgen, og det kan ta tid å få diagnosen. Når pasienter endelig får diagnosen FM, forventer de å få effektiv behandling. Men anbefalte tiltak som trening, medisiner og kognitiv adferdsterapi har moderat, kortvarig lindrende effekt. Det er nokså vanlig at pasienter prøver mange ulike behandlinger uten at de synes de har nevneverdig utbytte av det. Når pasienten ikke blir bedre av behandling, kan hun/han oppleve at helsepersonell trivialisere plagene, mener plagene er innbilte eller av psykologisk årsak, samt at de ikke gjør sitt beste for å bli bra. For pasientene kan dette være krekende. Vanskelige kliniske situasjoner oppstår, og helsepersonell kan synes at deres kunnskap ikke strekker til. Det er derfor behov for å bedre dagens behandlingstilbud, og at helsepersonell øker sin innsikt for å møte og forstå pasientene sine bedre.

Hensikten med vårt prosjekt var å utvikle et gruppebasert undervisningsprogram til pasienter med FM ved å bygge bro mellom kunnskap fra vår forskning om tilfriskningsprosesser blant tidligere pasienter som har blitt friske av FM, og erfaringer og fagkunnskap til et tverrfaglig rehabiliteringsteam med lang erfaring med å drive pasientundervisning til pasienter med artrose, revmatiske betennelsessykdommer og FM.

## **Kap. 2. Målsetninger og målgruppe**

### Hensikter

1. Utvikle et nytt pasientundervisningsprogram for pasienter med FM (gjennomført sept. 2017 – jan. 2018)
2. Undersøke om det nye pasientundervisningsprogrammet er gjennomførbart og gir mening i praksis, og event. justere innhold i forhold til pasienters og helsepersonells erfaringer (gjennomført februar 2018-des. 2018)
3. Evaluere betydning av pasientundervisningsprogrammet for pasienter på lang sikt 1-1.5 år etter avsluttet rehabiliteringstiltak og klinikere etter ca. ett års erfaring med å drive programmet (datainnsamling avsluttet mars 2020)

### Målgruppe for pasientundervisningsprogrammet

Deltagerne bestod av voksne personer som hadde fått diagnosen FM enten i primærhelsetjenesten eller ved Revmatismesykehuset A/S, Lillehammer. Alle var henvist fra enten fastleger eller sykehusets leger til et poliklinisk pasientundervisningstilbud for pasienter med FM ved sykehuset.

## **Kap. 3. Prosjektgjennomføring/metode**

### Arbeidsprosessen

Prosjektet fulgte et aksjonsforskningsdesign hvor utvikling ses som en prosess mellom utvikling og utprøving. Arbeidet ble ledet av to forskere og avdelingsleder av rehabiliteringsenheten ved Revmatismesykehuset A/S Lillehammer, og 12-16 ansatte deltok (leger, sykepleiere, psykolog, sosionomer, kostholdsekspert, ergoterapeuter og fysioterapeuter) med å lese kvalitative studier om pasienters sykdoms- og tilfriskningserfaringer og diskutere dem i plenum. Ut fra hva som kom fram om kliniske erfaringer i felles diskusjoner, ble det identifisert tema som ble diskutert videre i mindre

grupper. Både fellesdiskusjoner og smågruppediskusjoner ble ledet av forskerne som stilte spørsmål i tråd med kvalitativ intervjumetode. En forsker tok notater under fellesdiskusjoner, og diskusjon i små grupper ble tatt opp på lydbånd. Dette utgjorde vårt datamateriale som vi analyserte og presenterte for klinikere i påfølgende møte for å validere våre fortolkninger og for å komme videre i prosessen. Vi trengte 5 heldagsmøter (opprinnelig plan 3) til arbeidet. På det siste møtet ble det enighet om prosjektleders skriftlige forslag til begrunnelse og overordnet hensikt for intervensjonen, samt teoretiske modeller for å forstå FM (biopsykososial modell), tema som kunne adresseres ut fra faggruppens kompetanse (utviklet av prosjektleder basert på diskusjonene), og behandling (personlig, resurssorientert recovery-modell knyttet til forskning om bedringsprosesser, læring og pasientsentrert praksis). Intervensjonens innhold, timeplan og hvem som skulle samarbeide om ulike tema ble konkretisert av klinikerne.

Før vi prøvde ut intervensjonen i praksis ble prosjektplanen forelagt Regional Etisk Komité som ikke fant prosjektet fremleggelsespliktig. Prosjektet er godkjent av Norsk Samfunnsvitenskapelig datatjeneste. Intervensjonen ble så prøvd ut i praksis for fire grupper (opprinnelig plan 3). Den første pasientgruppen (n=11) og helsepersonell (n=8) som stod for undervisning ble intervjuet i fokusgruppeintervju om hva de syntes om intervensjonen de hadde deltatt i og om det var noe som burde endres. Etter dette ble det gjort mindre praktiske justeringer. Tre pasienter i neste gruppe ble intervjuet individuelt om det samme uten at det kom fram noe som førte til nye justeringer av innholdet. Betydning av pasientundervisningen ble evaluert ved hjelp av spørreskjema og individuelle intervju. Alle pasientene ble bedt om å besvare spørreskjema før, umiddelbart etter intervensjon, etter 6 måneder og etter ett år. I tillegg ble 9 pasienter intervjuet individuelt mens de deltok i pasientundervisningsprogrammet om sine sykdomserfaringer. Etter 1-1.5 år ble 11 pasienter intervjuet individuelt om hva som hadde skjedd i løpet av året etter avsluttet program, og 8 av personalet som hadde erfaring med programmet, ble intervjuet om sine praksiserfaringer (lengre oppfølgingstid enn planlagt).

#### **Kap.4. Resultater, vurdering av effektmål og resultatvurdering**

##### ***Tiltakets rasjonale og innhold***

Ut fra diskusjonene ble det klart at helsepersonell var usikre på om deres tiltak, som var i tråd med EULARs kunnskapsbaserte retningslinjer, hadde den effekt som var forespeilet i retningslinjene. De var også usikre på hvordan bidragene fra de ulike profesjonsgruppene hadde betydning da verken intervensjonen eller de ulike komponentene hadde tydelige hensikter. Det var også en viss frustrasjon over at pasientene ikke nødvendigvis fulgte rådene som de ga, og kunnskap om motivasjonsteknikker ble etterlyst. Imidlertid hadde personalet erfaring for at pasientene hadde stor nytte av å diskutere sine erfaringer i gruppene.

Rasjonale for det nye pasientundervisningsprogrammet er begrunnet i forskning om biologiske, psykologiske og sosiale endringer knyttet til FM synliggjort vha. en *biopsykososial modell*. Hensikten er å redusere pasienters livsstress ut fra en begrunnelse om at stress kan vedlikeholde og forhindre tilfriskning fra FM. Basert på forskning om pasienters sykdomsfaringer, tenker vi at det er stressende å leve med uforståelige, uforutsigbare og u håndterlige symptomer som invaderer og forstyrrer dagliglivet, og at stress i livet i sin alminnelighet kompliserer det hele. I programmet utforskes sammenheng mellom

symptomer og dagligliv, gjøre endringer i vaner og rutiner for å redusere stress og etter hvert bygge opp sin toleranse for stress. I motsetning til tidligere hvor helsepersonell lærte pasienter ulike strategier for å bedre livsstil og helse, samarbeider helsepersonell i det nye programmet med pasienter om å finne ut hva de kan gjøre av tilpasninger i hverdagen for å leve et meningsfullt liv i tråd med en *personlig ressursorientert tilhelingsmodell*. Ulike tema knyttet til livsstress presenteres av helsepersonell, og gjennom praktiske øvelser og erfaringsdeling utforsker pasientene sine erfaringer. Det ble gjort mindre justeringer av programmet etter første gruppe, bl.a. kortere møtedager og etter hvert færre møtedager (fra 10 til 8 ganger) med kortere intervaller mellom kursdagene.

### **Pasientundervisningsprogrammets betydning**

For pasientene: Pasientenes fortellinger etter 1-1.5 år viste at de var fortsatt engasjert i å tilhele seg og sine liv. I tiden etter deltagelse i programmet hadde de gjort en rekke mindre og større endringer i hverdagslivet; f.eks. skaffet avlastning til pass av barn, varierte mellom å gjøre belastende og mindre belastende aktiviteter i det daglige, gikk regelmessig på tur i skog og mark som avkobling og for å bli i bedre form, praktiserte medisinsk yoga eller andre meditative øvelser for å roe seg ned. Alle, unntatt en som kun hadde deltatt i programmet 2 dager, sa at de hadde flere gode dager enn før og hadde håp om fortsatt bedring.

For helsepersonell: Etter ett års erfaring med å drive det nye tiltaket, snakket helsepersonell ikke lenger om pasienters negative holdninger, manglende motivasjon og mye sykdomssnakk. De mente at mer positivitet var kommet inn i gruppene, og pasientene syntes å ha tro på fremtidig bedring. De syntes det var utfordrende å oppdage og heie på pasienters fremskritt da fremgangen var liten under kurset. Selv om de visste at det var å forvente, lurte de på om dette førte til noe på lengre sikt. Klinikernes omtalte seg nå som et team som arbeidet sammen mot et konkret mål, og de så betydning av sitt eget bidrag inn i et større hele. De møttes nå til et 15 minutters oppsummeringsmøte på slutten av kursdager for å reflektere sammen med resten av teamet om dagens erfaringer. På bakgrunn av kliniskernes spørsmål om og i så fall hvordan pasientundervisningen hadde betydning på sikt, bestemte prosjektleder seg for å intervju pasientene på nytt 1-1,5 år etter deltagelse i undervisningen. Dette både utvidet og forlenget prosjektperioden.

### **Kap. 5. Oppsummeringer og videre planer**

**Mellom kreativitet og systematikk.** Dette prosjektet har vokst frem undervegs og blitt mer omfattende enn opprinnelig planlagt. Kunnskapsutviklingen har vært en prosess frem og tilbake mellom fagkunnskap, praksiserfaringer, teori, og forskning, og det innebar betydelig samhandling mellom de aktørene som har deltatt. Gjennom prosessen har nye spørsmål dukket opp som det har blitt tak i. Gjennom åpenhet, refleksivitet, fleksibilitet og systematisk utforskning har prosessen drevet kunnskapsutviklingen fremover. Vår systematiske måte å gjennomføre prosjektet på har ført til at vi har fått mer ut av prosjektet enn «produktet» intervensjon. Samhandling betyr gjensidig respekt for hverandres kunnskapsbidrag, og dette har styrket det kliniske teamet. Arbeidsprosessen førte til at klinikerne fikk eierskap til intervensjonen, og dermed tok de ansvar for implementering i praksis. Vi vil argumentere for at vi har lyktes med å utvikle en kontekstualisert kunnskapsbasert praksis av betydning for pasienter.

Ved at vi har dokumentert så mye i denne prosessen, både oppsummerende feltnotater, opptak av diskusjoner og intervjuer av deltagere, har fagutviklingsarbeidet gitt gode data til å kunne gå tilbake for å videreutvikle forståelse om hva og hvorfor ting skjedde

underveis. Prosjektet ble utvidet ett år i forhold til opprinnelig prosjektplan da det ble en integrert praksis på sykehuset hvor lønnskostnadene ble dekket av sykehuset. På denne måten ble flere pasienter inkludert i prosjektet. Ved også å følge opp pasientene over lengre tid enn opprinnelig planlagt, klarte vi å få vite hva pasientene hadde drevet med etterpå.

**Brukerinvolvering.** Brukerinvolvering ses som et absolutt gode i dag, både innen forskning, i utvikling av klinisk praksis og i politisk utforming av helsetjenester. Dette er i stor grad basert på en demokratiserings- og pasientrettighetstankegang. Vår søknad ble forelagt og støttet av Pasientbrugerutvalget ved sykehuset. I utviklingsfasen ble klinikerne ansett som brukere. Pasienter deltok ikke her da vi antok at det ville bli enklere å få i gang diskusjoner med klinikere uten pasienter tilstede. Det viste det seg å være riktig, da klinikerne satte ord på egen faglig og personlig usikkerhet, samt utfordrende erfaringer med pasienter og kollegaer i helsevesenet. Pasienters «stemme» og erfaringer ble imidlertid ivaretatt i utviklingsprosessen ved at vitenskapelig artikler om pasienterfaringer og teorier om personlig tilhøringsarbeid ble brukt i diskusjoner. Artikler om pasienterfaringer fikk betydning for å sette ord på kliniske praksiserfaringer. Vi mener dermed at vi har lyktes med å bygge bro mellom pasienterfaringer, kliniske erfaringer, fagkunnskap og empirisk forskning (samproduksjon av kunnskap). Under evaluering av pasientundervisningen ble pasienter sett på som brukere av programmet, og deres meninger fikk betydning for å evaluere og justere programmet. Tidligere kursdeltagere ble invitert til nye kurs for å fortelle om sine erfaringer. Samproduksjon av kunnskap er videreført i det pedagogiske opplegget i pasientundervisningsprogrammet da nye forståelser av den enkelte pasients erfaringer og liv utvikles gjennom samarbeid mellom pasienter og helsepersonell. Kursene blir dermed ikke statiske og er i stadig utvikling.

### **Formidling**

**Muntlig:** Klinikerne har blitt invitert til å presentere arbeidet sitt i lokalforeninger i Norges Fibromyalgiforbund i Innlandet. Prosjektleder var invitert til «kafediskusjon» ved Rehabiliteringskonferansen Innlandet 2019 med et kort innlegg om innhold og dermed spørsmål og refleksjon blant helsepersonell rundt bordet, og hun har også presentert prosjektet i et møte om Kvinnehelse arrangert av Norske Kvinners Sanitetsforening i 2019. I tillegg er et abstract om intervensjonen akseptert til muntlig fremlegging ved en konferanse arrangert av the World Confederation for Physical Therapy, Mental Health i Helsingfors i mai (foreløpig utsatt pga korona).

**Skriftlig:** Så langt har det blitt produsert et bokkapittel hvor vår arbeidsprosess brukes som case (1), en fagartikkel om arbeidet vårt for klinikere innen revmatologi (2) og en vitenskapelig artikkel er sendt til et internasjonalt tidsskrift i juni 2020 (3) hvor vi beskriver pasientundervisningsprogrammets rasjonale, hensikt, innhold og betydning.

Videre planer: Pga. koronapandemien og permitteringer ved Revmatismesykehuset, Lillehammer måtte vi utsette planlegging og gjennomføring av et seminar for å formidle resultater av prosjektet vårt til pasienter og ansatte i primærhelsetjenesten i Innlandet. Vi håper at det snart blir mulig å presentere prosjektet via nett for helsepersonell i primærhelsetjenesten og pasienter (muligens vår 2021). Det er generert mye data som gjenstår å analysere. Det er påbegynt et arbeid hvor vi undersøker om det er samsvar mellom målinger gjort med spørreskjema og pasienters bedringsfortellinger for å undersøke hvilke spørsmål kan være mest relevant å stille for å evaluere pasienters utbytte av lærings- og mestringsopplegg. Dataene fra intervjuer av helsepersonell vil bli analysert for å

undersøke hvordan tenkemåter blant klinikere kan endre seg i en samproduksjonsprosess. Klinikerne arbeidere nå for å integrere sin kunnskap i andre praksiser ved sykehuset. Prosjektleder har lyktes å få midler til en postdoktor fra Fysiofondet. Postdoktor startet 1. august 2020 og skal videreutvikle og tilpasse modellen til bruk av fastleger og fysioterapeuter i primærhelsetjenesten (yrkesgruppene som hyppigst møter disse pasientene).

Arbeidet med dette prosjektet har derfor blitt mer omfattende og fått større betydning enn det vi i utgangspunktet så for oss. Både tiltaket og måten å arbeide systematisk på, får betydning for veien videre både i klinisk praksis og i forskning.

### **Produserte publikasjoner vedrørende prosjektet**

1. Mengshoel AM, Sallinen M. Bringing qualitative research into rehabilitation – a worked example of developing a rehabilitation program for patients with fibromyalgia. In Hayres CM, Muller D: Enhancing Health Care and Rehabilitation – the impact of qualitative research. TRC Press Francis & Taylor Group 2019; Chap 14: 223-242.
2. Mengshoel AM. Nytt rehabiliteringstilbud til pasienter med fibromyalgi. Best Practice Revmatologi 2019; nr 34: 8-10.
3. Mengshoel AM, Skarbø Å, Hasselknippe E, Petterson T, Brandsar NL, Askmann E, Ildstad R, Løseth L, Sallinen MH. Enabling personal recovery from fibromyalgia – theoretical rationale, content and meaning of a person-centred, recovery-oriented programme. (sendt til internasjonalt tidsskrift juni 2020)

**Book chapter in: Hayres CM & Muller D:  
Enhancing Health Care and Rehabilitation – the  
impact of qualitative research. TRC Press Francis &  
Taylor Group 2019**

**Chap 14: 223-242:**

**Bringing qualitative research into rehabilitation – a  
worked example of developing a rehabilitation programme for  
patients with fibromyalgia**

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## **Abstract**

Researchers and a multidisciplinary clinical team collaborated on the development of a rehabilitation programme for patients with fibromyalgia (FM). In this chapter, we describe the process of developing the programme, which involved reflecting across evidence, patient-centeredness, and clinical experiences. Pulling the different knowledges together, we applied condition-oriented evidence and a biopsychosocial model to demonstrate the complexity of FM and determine the target of the programme. The programme's patient-centred approach was supported by patient-oriented evidence, theories of suffering and personal recovery, and clinical experiences, which fit together into a personal resource-oriented recovery model. Our experience was that applying a qualitative explorative approach and incorporating evidence from qualitative studies enhanced our reflexivity. Moreover, a 'bottom-up' working process resulted in a broad understanding about FM, what FM is like to live with and what a personal recovery process implies for a patient.

## **List of keywords**

Fibromyalgia – development of rehabilitation programme – working process – qualitative inquiry – life stress

## **Introduction**

Fibromyalgia (FM) is a chronic musculoskeletal pain condition with no known cure. Present clinical guidelines are based on effect studies showing limited effects, and the guidelines have not taken into account whether such programmes are found meaningful to patients. Qualitative studies describe how complex and challenging it is for a patient to live with FM, but suggest that patients can overcome it and even become symptom-free again. The gap between quantitative and qualitative evidence was the reason the present authors initiated a project to develop a new rehabilitation programme for patients with FM. The programme was developed in collaboration with a multidisciplinary team with clinical experiences in delivering group-based educational programmes for patients with inflammatory or degenerative musculoskeletal diseases, as well as FM. In the present chapter, we explore our joint efforts in reading and discussing qualitative studies to develop the new rehabilitation programme. To develop a logical interconnected programme, we had to unpack and reflect on the various knowledges underpinning our understandings. First, we briefly describe some of the discourses embedded in rehabilitation that came into play during our work, followed by a short review of the evidence about the FM condition and patients' experiences. We conclude by describing our working process, dilemmas in clinical practice and how a logical, interconnected programme was reached.

## **Discourses framing the clinicians' rehabilitation context**

According to Wade and de Jong (2000), rehabilitation aims to help patients with functional restrictions acquire knowledge and skills to maximise their participation in social settings, minimise pain and relieve distress experienced by the patient, family, and caregivers. However, rehabilitation is a hybrid discipline with theoretical roots in the disciplines of the various health professionals engaged in the field; as such, it lacks a unique and unified theory detailing the

parameters of rehabilitation practice (Siegert, McPherson, and Dean 2005). Furthermore, perhaps more than in any other area of medicine and health care, rehabilitation practice is highly influenced by societal views on disability and disabled people, as well as people's general expectations regarding getting appropriate and effective help from health services when needed. Rehabilitation practice is also highly framed by health politics and economics, which determine what is possible to deliver. Hence, health professionals have to take into consideration several discourses beyond their professional knowledge. In addition, there are discourses embedded in clinical practice that determine what the best clinical practice is and how it should be delivered. In the process of developing the rehabilitation programme, the clinicians frequently referenced discourses from evidence-based practice (EBP) and patient-centeredness.

EBP is broadly embraced by health professionals, also within the field of rehabilitation (Dijkers, Murphy, and Krellman 2012). The idea behind EBP is that practice should be informed by the best evidence from research (Jacobson et al. 1997). The scientific studies included in the EBP model mainly address issues around a disease or illness condition, and how a condition should be treated (Greenhalgh 2014). In other words, EBP relies on condition-oriented evidence. Somatic conditions are often described in terms of typical symptoms, biological dysfunctions or deficits related to cause(s), manifestations of a disease, and typical functional limitations considered to be consequences of a disease (Hofmann 2001; Wulff, Pedersen, and Rosenberg 1999). Therapies are tailored to these deviations in order to normalise them, and effects of therapies are determined by assessing if the therapies lead to less typical condition-related deficits and consequences (van Riel and Fransen 2005). Evidence from randomised clinical trials (RCTs) is considered to be the most reliable design for determining the most effective and appropriate therapy (Anjum, Kerry, and Mumford 2015). In order to ensure that the effects are likely to happen across individuals and contexts, personal and contextual factors are controlled

for in the design (Kerry 2017). Thus, the assumption underpinning condition-specific knowledge is that people with the same diagnosis—regardless of who they are, the contexts in which they are living and who is delivering the programme—can successfully be treated by similar therapies.

Another central discourse within rehabilitation referred to by the health professionals who participated in this project was person- or patient-centred practice (Gluyas 2015; Sacristan 2013). Central to patient-centred practice is the idea that patients are regarded as autonomous people who have the right to be heard and actively involved in decisions concerning their life and rehabilitation needs (Gluyas 2015). Further, the patients should be treated with respect by health professionals and a paternalistic attitude should be avoided (Gluyas 2015; Sacristan 2013). In this context, health professionals are expected to clarify a patient's concerns and beliefs, inform them about treatment options, and empower the patient to make decisions, set their own attainable goals and engage in actions to reach those goals. This approach recommends that clinicians include goal-setting, motivational techniques, and appropriate ways of communicating in their care provision (Gluyas 2015). The person-centred practice focuses on the individual patient's wishes and needs, but is considered to be an integrated part of EBP (Sackett et al. 2007), as illustrated in Fig. 1.

### **A brief review of condition-oriented evidence on fibromyalgia**

Fibromyalgia (FM) is a common disorder with a prevalence estimated to be about 3% to 5% in the general population (Queiroz 2013). FM is a persistent widespread musculoskeletal pain condition accompanied by an array of other symptoms such as fatigue, sleep disturbances, memory problems, irritable bowel, low activity tolerance, and several complaints related to the autonomous system (Choy 2015). Psychological changes are also reported: depression, illness

worries, anxiety, inadequate coping skills and psychosocial distress (Anderberg et al. 2000; Ercolani et al. 1994; Gupta et al. 2007; Kurtze, Gundersen, and Svebak 1999; Turk et al. 1996). Typical consequences related to FM are impaired daily functioning, and difficulties fulfilling social obligations and continuing to work (Liedberg and Henriksson 2002; Sallinen et al. 2010).

The aetiology of FM is unknown, but stress has been suggested as a plausible triggering factor, as high or longstanding exposure to mental or physical distress has been observed in the period before the onset of FM (Wallace and Wallace 2014). Stress also seems to aggravate symptoms (Yunus 1994). The pathogenesis of FM is explained by hypersensitivity within the central nervous system (Ang and Wilke 1999; McVeigh et al. 2003; Winfield 1999). This means that pain may result from both an amplification of normally pain-free sensory stimuli or the prolongation of normally painful stimuli. An explanation of several other symptoms is related to hyporesponsiveness within the hypothalamic-pituitary-adrenal axis (Crofford et al. 1994; Griep, Boersma, and deKloet 1993), indicating the existence of inappropriate responses to stressors (Neeck and Riedel 1994). Thus, it has been suggested that biological responses to long-term ‘fight and flight’ arousal from stress may exhaust systems (Coopens et al. 2018; Van Houdenhove, Egle, and Luyten 2005).

Although FM is explained by biological deviations, these cannot be verified by conventional clinical examinations such as blood tests and radiological assessments. Persons with FM do not look sick, and therefore FM is invisible both from ‘the inside’ and ‘the outside’. Health professionals and other people in society may think that patients with FM are malingerers or hypochondriacs, and the symptoms are considered to be imagined or of a psychological nature (Mengshoel et al. 2017). Accordingly, the use of a diagnosis is questioned, and some argue that labelling the suffering with a diagnosis hinders recovery (Hadler 1996).

Systematic reviews of effect studies have been conducted in order to illuminate the best treatment approach for patients with FM. Based on these reviews, evidence-based clinical guidelines for FM have been developed that recommend the use of tricyclic antidepressive drugs, cognitive behavioural therapy, exercise programmes and patient education (Brosseau et al. 2008a; Brosseau et al. 2008b; Carville et al. 2008). However, a meta-analysis showed that antidepressant drugs had minor clinical improvement in pain reduction (Üdeyler, Häuser, and Sommer 2008). The authors expressed concerns as to whether the benefits were big enough, considering the potential side effects from long-term use. Several systematic reviews have concluded that exercise is an important form of therapy for patients with FM (Bidonde et al. 2014; Busch et al. 2002; Jones et al. 2006; Macfarlane et al. 2017; Sim and Adams 2002). Like drugs, strengthening or conditioning exercise programmes lead to some, but not lasting, symptom relief. Exercise leads to improved physical functioning, and an umbrella systematic review noted that physical activity at a moderate intensity level has no adverse effects (Bidonde et al. 2014). However, it should be noted that exercise must be performed on a regular basis to maintain its benefits.

Education programmes have been developed to help patients manage FM symptoms through learning about the condition and practicing appropriate coping skills. The content of these programmes varies, but in general they include lectures on pain mechanisms, encouragement to exercise regularly, and education in pain-management techniques including relaxation and adjusting daily activities to avoid overstrain (Goldenberg 2008; Mannerkorpi and Henriksson 2007; Mengshoel et al. 1995). Attempts may also be made to modify negative feelings, based on the assumption that negative thoughts and certain behaviours can maintain or aggravate suffering (Burchardt 2002). Patient education programmes overlap to some extent with

cognitive behavioural therapy (CBT). CBT is a psychological approach based on a theory that a person's beliefs, attitudes and behaviours play a central role in determining a patient's experience of suffering. The aim is therefore to change cognition and behaviour inspired by classical and operant learning theories (Davidson 2008). Systematic reviews have shown that patient education and CBT lead to clinically relevant improvements in pain, disability and mood, but the effect sizes are not large, and the effects often do not last (Bernardy et al. 2013; van Koulil et al. 2007). The limited effects of recommended therapies imply a need for developing new rehabilitation programmes.

### **A brief review of person-oriented evidence on fibromyalgia**

Several qualitative studies have been conducted to explore what it is like to live with FM. Bodily sensations of pain and fatigue are experienced as diffuse, with varying degrees of severity (Cunningham and Jillings 2006; Hellström et al. 1999; Råheim and Håland 2006). Many factors can trigger symptoms, but these may vary for no apparent reason (Sim and Madden 2008). This means that patients find their bodies unreliable (Råheim and Håland 2006; Söderberg, Lundman, and Norberg 2002), and they carefully monitor their activities to avoid 'overdoing it' (Cunningham and Jillings 2006; Mannerkorpi, Kroksmark, and Ekdahl 1999). Accordingly, both the fear of pain and the pain itself may disturb everyday habits and routines (Richardson, Ong, and Sim 2008). Daily life can be perceived as chaotic and beyond a person's own control (Grape et al. 2017), as activities are planned in accordance with day-to-day symptom levels, and are halted if these become worse (McMahon et al. 2012; Richardson, Ong, and Sim 2008). In this way, everyday life becomes ruled by incomprehensible bodily sensations (Åsbring and Närvänen 2004; Richardson, Ong, and Sim 2008; Schoofs et al. 2004). This can lead to grief over undone tasks and unfulfilled social obligations, and patients can be forced to delegate responsibilities to other people; as such, a patient's identity, social roles and relationships are

compromised (Richardson 2005). Patients also experience health professionals and others as questioning the ‘realness’ of their symptoms (Briones-Vozmediano et al. 2013; Dennis, Larkin, and Derbyshire 2013; Mengshoel and Heggen 2004), and they sometimes feel that their credibility and dignity are threatened (Åsbring and Närvänen 2002; Sallinen, Kukkurainen, and Peltokallio 2011). Thus, patients with FM have to face both the burdens of living with an inexplicable and disruptive illness and being disrespected by other people (Juuso et al. 2014).

It is often years before a diagnosis of FM is arrived at (Choy et al. 2010). During this process, the patients consult various medical specialists in order to rule out serious illnesses (Mengshoel et al. 2017). Immediate relief is experienced by patients when getting a FM diagnosis, as it means they are not suffering from any fatal or crippling disease (Madden and Sim 2006; Mengshoel and Heggen 2004; Undeland and Malterud 2002). However, the relief wanes over time when patients discover that the diagnosis neither validates their sickness nor is accompanied with effective therapy (Madden and Sim 2016). Patients often try several therapies without success, and when they do not become better, they often find that health professionals give up on them, perhaps thinking they are not doing their best to recover (Mengshoel et al. 2017). At this stage, patients are often told that they must accept the situation and learn to live with it, but the diagnosis provides little explanation of how to understand and live with FM (McMahon et al. 2012; Undeland and Malterud 2007). Often, patients are told to ‘listen to their body signals’ in order to learn what they can and cannot do. However, what is tolerable one day can be impossible the following day (Richardson, Ong, and Sim 2006). Thus, the body does not necessarily provide any definitive answer about how to adjust a life to an illness.

In acute pain conditions, pain is often related to injurious bodily incidents. This interpretation could also apply to incidents of pain aggravation in chronic pain conditions. In contrast, patients

who have recovered from FM understand symptom aggravation as the body's way of warning them about too much mental and physical strain over time (Mengshoel and Heggen 2004). This meaning was used by the patients as a guide to figure out what had to be done to achieve a less stressful life. New episodes of pain, after a patient had become healthy again, were even reversed by a temporary down-regulation of daily life (Mengshoel and Heggen 2004). Other researchers who have interviewed patients who have recovered from FM also find that symptoms are used as a resource for remaking a daily life they can tolerate (Grape et al. 2015; Sallinen et al. 2012; Wentz, Lindberg, and Hallberg 2012). In this process, symptoms gradually disappear (Grape et al. 2017). This suggests that life stress can be heightened by uncertainty related to the diagnostic process, the ambiguous meaning of the diagnosis, the lack of efficient therapies and degrading attitudes from health professionals and other people. Of course, it is also stressful to live with an unmanageable illness that disrupts daily life, social identity and roles. Accordingly, making sense of the illness situation and adjusting one's life situation accordingly can be important ingredients for modulating stress.

Summing up the evidence, low effects of pharmacological and non-pharmacological therapies for FM have been demonstrated by the condition-oriented evidence, implying that the development of new rehabilitation programmes for these patients is needed. Both quantitative and qualitative studies show, in various ways, the complexity of symptoms and their personal and social consequences—life stress, too, may play a role, for example in perpetuating symptoms. Few studies address patients' recovery experiences, but evidence from qualitative studies brings hope that patients can overcome FM. We therefore wanted to incorporate this knowledge into the process of developing a new rehabilitation programme. In the following section, we describe our working process.

## **The working process of developing a new rehabilitation programme**

### **The context and participants**

The project was undertaken at the Lillehammer Hospital of Rheumatic Diseases, in Norway. This is a specialised hospital delivering medical diagnostics and therapies to patients with chronic musculoskeletal disorders, as well as multidisciplinary rehabilitation programmes for in- and outpatients. Over the years, the staff has been involved in several research projects, and the hospital has a culture that encourages continuous debates among the staff aimed at improving practice. Their rehabilitation programme for patients with FM followed the clinical evidence-based guidelines, and included a combination of patient education, CBT and conditioning exercise. A multidisciplinary team of twelve to fourteen health professionals participated in the present project. The team was comprised of nurses, occupational therapists, physicians, physiotherapists, social workers, a psychologist, and a dietician. Most of the team members had worked for many years in rehabilitation for patients with musculoskeletal disorders. Several had further education, e.g. in counselling, and all were recognised within their professions for their competency. The head of the unit—an occupational therapist—strongly supported the developmental process and attended all of the workshops. The clinicians' reasons for participating were varied, from professional curiosity and a wish to do better, to become stronger to resist external threats of future official limitations in funding the programme.

The developmental process was led by researchers (the authors) from the University of Oslo. We had prior clinical experiences in delivering rehabilitation within mental health, primary health care and rheumatology as physiotherapists, and we had participated in research projects that lay broadly within the field of rehabilitation but with a special focus on FM. The development of the rehabilitation programme was funded by the Norwegian Foundation for

Health and Rehabilitation (no. 2017/HE2-184218) and approved by the Norwegian Data Inspectorate for Research (no. 2018/57956/3/EPA).

### **The researchers' pre-understandings**

The project leader (AMM) holds a part-time position at the hospital and knew the context and the health professionals; to a certain extent, she occupied an insider position on the project. Nevertheless, her knowledge about the clinicians' rehabilitation practice for patients with FM was fragmented. The other researcher (MS) had an outsider position; she did not know the participants beforehand, was unfamiliar with ongoing discussions and, being Finnish, was unfamiliar with the Norwegian rehabilitation context. The researchers' diverse positions nurtured the process, helping to develop a good atmosphere for sharing and discussing experiences and asking about issues that, from an insider position, were likely taken for granted and thus not detected.

The researchers had the shared experience of clinicians often being up-to-date in quantitative, condition-oriented research, as clinicians learn to read and critically appraise quantitative studies through their professional education and courses in EBP. But reading and evaluating qualitative studies do not seem to be included in such curricula. Clinicians may feel that qualitative studies report about experiences that are too individual to be transferable to their patients. This raises a timely question about the validity and transferability of research in a clinical context. Quantitative studies illuminate trends and inform about 'mean' patients that do not necessarily exist in the real world (Anjum, Kerry, and Mumford 2015). This means that it is challenging to translate evidence from quantitative effect studies to provide valid information about an intervention's potential significance to an individual patient in a clinical setting (Haynes, Devereaux, and Guyatt 2002). Qualitative studies, in turn, are highly situational and nested in the culture and contexts in which the informants live their lives (Green and Thorogood

2014). Accordingly, informants' experiences do not necessarily match a specific patient in another clinical context. Nevertheless, in our opinion, both qualitative and quantitative studies can inform and enhance clinical reflexivity and reasoning, but neither can dictate what clinicians should do in practice. We therefore acknowledge that there is a gap between research and practice. Because the clinicians claimed to practice patient-centred care and to take a patient's perspective into account in their practice, we found it relevant to bridge this gap by bringing in patient-oriented evidence, discussing it in light of clinicians' own experiences.

We had no given 'formula' to implement, but we envisioned that, together with the clinicians, we could co-develop a programme tailored to patients' personal recovery processes. By talking across clinical experiences, scientific and professional knowledges, we assumed that everyone's reflexivity would be encouraged, including our own. It is a common opinion that knowledge from evidence should be transferred to clinicians in a kind of 'one-way road' (Lockwood, Armstrong, and Grant 2004; Manns and Darrah 2006)—however, this contrasted with our goal of establishing a 'bidirectional road'. In retrospect, we discovered that the process can even be described as a 'multidirectional web of roads'.

### **Workshops and participants' roles**

In agreement with the head of the rehabilitation unit, we planned to arrange three full-day workshops within a one-month interval. The workshops served as an arena for expressing ideas, sharing experiences and searching for new understandings in accordance with a participatory, action research method. After the third workshop, the content of the programme had not yet been clarified, so a two-day workshop was arranged to concretise the content and procedures of the programme.

Before each of the first three workshops, the researchers distributed two or three qualitative papers, which were then read by the clinicians. The head of the rehabilitation unit encouraged the professionals to present these papers and discuss them in regular literature meetings at the

hospital. She also raised questions for the researchers about what needed to be clarified and further elaborated upon. In addition, between the workshops, she had informal meetings with the professionals in which they continued their reflections and eventually agreed to try out new practical solutions in their clinical practice. The researchers moderated or observed the group discussions, making notes and analysing and summarising discussions orally and in writing, thereby also linking the process to evidential and theoretical understandings of patients' illness and recovery experiences.

## **Bringing qualitative studies and inquiry into the process**

### **Reflecting across qualitative studies and clinical experiences**

During open plenary discussions, qualitative studies were used to facilitate discussions to explore how the health professionals understood and found meaning in the literature and whether the studies resonated with what their patients had told them. For the first meeting, participants read systematic reviews of qualitative interviews of patients with FM that addressed inexplicable, unpredictable pain and fatigue, diagnostics, activity and identity constraints, and explanations of suffering (Mengshoel et al. 2017; Sim and Madden 2008; Toye et al. 2013). This raised reflections in the meeting about uncertainties regarding the meaning and managing of such a complex illness. To further enhance these reflections, two additional texts were selected for reading before the second workshop: a paper discussing the importance of making sense of bodily sensations from a patient perspective (Corbin 2003) and a narrative review of recovery interpreted as a personal learning process (Mengshoel and Grape 2017). The importance of making sense of an unfamiliar body and its relationship to daily life were discussed further in the third workshop, inspired by papers addressing two topics: what it is like for patients to live with and be in treatment for FM (Ashe et al. 2017), and the importance for patients with chronic illnesses to take action to create order in their life situation (Kralik et al. 2004). Regarding the latter, the authors discussed professional-driven vs patient-driven

approaches, which inspired a lively discussion among participants about the professionals' roles. The clinicians discovered that what they had read in the papers corresponded and gave meaning to what they had heard from their patients. Even more important, these papers also facilitated reflections about situations from their own clinical practice and their relationships with their patients. While the discussions were not always centred on the papers' main topic, they all related to concepts or details in the papers that helped the clinicians articulate their own thoughts. Hence, the papers were helpful in bringing otherwise private reflections into the 'public' sphere.

### **Thematically-focused explorative reflections**

The open cross-talks could often seem fragmented and difficult to follow. Therefore, we decided to arrange group discussions about the themes that we identified when we created the summaries from the prior meeting, such as the meaning of the diagnosis to patients and to professionals. These discussions were initially performed in a large group, but when we realised that some participants appeared less comfortable voicing their thoughts in a big group, the group was divided in two. In small groups of six or seven, everyone had more space and opportunity to express themselves, and the reflections became more focused and went deeper into the given topic. Here, too, the researchers' role was to facilitate reflections among the clinicians, but this time their role also entailed keeping the reflections focused, so in-depth information about a topic could emerge. As both researchers were engaged in moderating these discussions, the discussions were audio-recorded.

### **Importance of writing up summaries**

After each workshop, the researchers developed written reports summing up what was said in the open and thematically-focused discussions. We discussed our own experiences, notes and audio-recordings, and developed themes that were then presented at the next workshop. These presentations served to validate our interpretations, to keep the process on track and promote further progress. For the final workshop, the researchers drafted a document in which the

various themes developed in the process were pulled together and given meaning with the help of theoretical models. This draft was sent to the clinicians before the workshop, and helped both the researchers and the clinicians see how various knowledges were connected and formed a logical whole. After more clarifying discussions, the draft was used to translate the programme into clinical procedures and actions. At this point, the clinical team leader took charge of the process to concretise a timetable for the rehabilitation intervention, including what would be done and by whom.

### **Dilemmas experienced in clinical practice**

During the developmental process, several dilemmas in clinical practice became apparent that were not explicitly addressed in the scientific literature. For illustration, we provide some examples below. These dilemmas could not be solved through procedures, but a shared awareness about these issues was found to be valuable. It made us realise that dilemmas can appear when different logics and meanings are set in motion.

#### **A diagnosis with various meanings in clinical practice**

The papers synthesising qualitative studies about patients' experiences of FM diagnosis (Mengshoel et al. 2017; Sim and Madden 2008) led to lengthy discussions. One discussion addressed the various attitudes towards the FM-diagnosis among Norwegian rheumatologists that either accepted the reality of symptoms or considered them an exaggeration of trivial complaints. This discussion also linked to an ongoing debate in Norway about whether hospitals specialising in rheumatology should deliver services to these patients. To some extent, the clinicians felt they had to defend their practice against external forces. These controversies are attached to an ontological question as to whether subjective illness experiences are reliable without any objective verification of biological malfunction. Nevertheless, the team was ambivalent about whether the diagnosis was good or bad for the patient. On the one hand,

getting a ‘proper’ diagnosis halted the patients’ cycle of seeing new physicians. On the other hand, it was questioned whether the FM diagnosis could attach a patient to a sick role and thus strengthen sickness behaviour and hamper the recovery process. This ambivalence can be interpreted as rooted in various discourses: fear of medicalisation, for example, or health professionals’ imperative to help ill people. The team also expressed different views about the clinical relevance of the diagnosis. The medical doctors used the diagnosis as a tool for validating FM from a medical perspective and explaining the patient the biological background of FM and the medical treatment approach they eventually chose. The allied health professionals valued the diagnosis for more instrumental reasons, as it helped them stop the patients from searching for new interpretations. For them, the diagnosis could also mean a fundamental change in a patient’s focus from spending energy to convince health professionals about the reality of their suffering into starting their recovery work. This reflects the health professionals’ various knowledges and interests within their work.

### **Ambiguous understandings of acceptance and normality**

The professionals acknowledged that their patients with FM were going through at least two processes simultaneously: namely, a process of losing or giving up something that was taken for granted earlier and a process of reaching for recovery. The constant yearning for life as it used to be, often expressed by the patients, seemed to reflect an ambivalent attitude towards starting a recovery process. The professionals pointed out that they felt it is important to explore this ambivalence with the patient in order to enable positive development and acceptance: for example, asking, ‘What can you do to make your situation better, and what is holding you back?’ The patient must accept the situation as it is in that moment, but at the same time not resign themselves to the idea that it will be the same in the future. Acceptance and normality were closely connected concepts, both relating to a personal process of recovery. Patients’ grief over the normal life they had lost and uncertainty about their symptoms could be relieved when

patients realised that their experiences were shared by other patients with FM—i.e. these experiences were normal for FM. However, in a process of recovery, a new meaningful normality had to be created. This means that patients had to accept that they would not necessarily return to life as it used to be, but accept that another normal life could be rebuilt that could be as good as the previous one. Acknowledging the patients' processes meant that the health professionals recognised the personal processes that patients were undergoing, but they considered these processes barriers to their own work rather than something to be directly acted upon. Acceptance and normality can thus have both positive and negative connotations in a person's recovery process.

### **Ambivalences in interpreting outcomes**

The different meanings of the concept of normality were also discussed in relation to how and by whom progress in the patient's process can be measured or evaluated. It was acknowledged that sometimes the measurement tools that the professionals considered reliable might not detect small changes that were nonetheless perceived as meaningful by the patients. Alternatively, there could be times when there was a clinically significant improvement in objective measurements but the patient did not see the benefit. It was also stated that encouraging the patient to pay attention to even a small improvement was important to keep up motivation and to prevent drop-outs. The need for developing follow-up strategies after the rehabilitation programme was perceived as important because 'recovery does not happen in the blink of an eye—rather than that, it takes time and effort'. These reflections demonstrate that two different interpretations of recovery are operating simultaneously: recovery linked to improved outcomes (i.e. reduction in disease/illness symptoms) caused by time-limited and effective interventions; and recovery linked to patients' perceptions of wellness and satisfaction as time-consuming processes.

### Uncertainties related to own professional role

The professionals emphasised that the rehabilitation process is in fact the patient's process and that the pace of the patient should be respected. However, they found it problematic if the patient either 'rushed forward too quickly and crashed' or 'parked here and did not want to move forward'. From the professionals' vantage point, the clinicians were put in an uncertain position: to interfere or not to interfere? They also discussed whether it is ethically acceptable to give up trying to motivate and guide the patient if the patient was not ready or willing to take action her/himself. It was seen to be against the idea of person-centred care if the professionals made a decision to halt the rehabilitation, but it was also their clinical experience that there was no point to continue if the patient was reluctant. Whether or not to interfere was also discussed with regards to patients who repeatedly told the same story about suffering. They felt it was important to listen to a patient's stories, but at the same time this recurrent narrative hindered the patient from starting to search for possibilities to do something about their situation. In this case, a dilemma arose, weighing opposing aims: respect a patient's autonomy or the professionals' obligation to be effective.

The syntheses also brought the issue of tolerating professional uncertainty into the discussion (Mengshoel et al. 2017; Sim and Madden 2008). Uncertainty was reflected upon regarding how to respond to certain questions from their patients, i.e., what is wrong, why this pain, and how can I understand and manage unpredictable variations in symptoms? The professionals felt they lacked good answers to these questions and were therefore uncertain about their own professional expertise. Although work experience, further education and reading research reports had increased their competence and knowledge over the years, there was still no consensus in the literature that helped them give an explicit answer to the patients' questions. Sometimes the clinicians also felt frustrated with these patients when nothing seemed to help. They pointed out that their uncertainty was easily transferred onto the patients, and in such a

situation it could be difficult to convince the patient about the benefits of the rehabilitation programme or to motivate the patient to take an active role in their rehabilitation. In turn, patients' earlier negative experiences of encounters with health professionals were sometimes reflected in their relationship to their new providers. The professionals therefore had to actively work to build a good relationship with patients with FM—more so than with other patients they met through their work. Their statements suggested that their relationships with patients with FM were fragile, and the professionals 'watched their steps' carefully. This reflects the fact that, although health professionals feel they should be personal they also has to behave as experts in their practice, these two aims are not always in harmony.

## **The bricolage of knowledges underpinning the new programme**

### **The programme's 'why'**

A biopsychosocial model helped us display the condition-oriented evidence about FM to help our interpretations by demonstrating how complex FM actually is, as well as how biological, psychological and social factors may interact with each other. This made it easier for us to understand how life stress can perpetuate symptoms and deficits of FM and, accordingly, why tailoring a rehabilitation programme to modify life stress may be appropriate (Fig. 2). Moreover, the biopsychosocial model makes it plausible that changes in, for example, how a patient perceives a situation or how their life is lived can influence biological, psychological and social factors. In this way, the programme's purpose and rationale could be explained by condition-oriented evidence.

The biopsychosocial model was already a pillar for the clinicians' work, and accordingly the modelling of the programme's 'why' was easily adopted. However, it was difficult to see how the programme's content could be modelled with using a biopsychosocial model. In support of this notion, Epstein and Borrell-Carrio (2005) conclude that a biopsychosocial model cannot

guide a practice in choosing an explicit or implicit therapeutic methodology; rather, it serves more as a vision for practice, such as in the present case.

### **The programme's 'what'**

Both the researchers and the clinicians held the opinion that a rehabilitation programme for patients with FM could not be delivered in a 'one-size-fits-all' fashion but had to be tailored to the needs of each patient, in accordance with the ideals of patient-centeredness. For the clinicians, this meant that the patient must determine what they need and what the right solution is for them to reach their life goals. However, patient-oriented evidence shows that patients struggle to understand how symptoms relate to what they are doing in daily life. It is therefore not a given that patients with FM know what they need. They need hints about what to look for, and they must explore and discover what brings stress into their lives and find out how to modify, for example, social obligations, and their own and others' expectations and priorities. One premise underpinning this view is that a patient will be willing to take actions if they find them meaningful and realistic.

The next question to consider for clinical work is, how can health professionals help a patient develop insights into how symptoms relate to what they do in daily life? The literature on patient-centeredness does not focus on the importance of a patient's meaning-making process, but according to person-oriented evidence about FM, this is important. A personalised resource-oriented recovery model highlights the patient's strengths and resources for exploring and discovering how illness relates to their own life project in order to get their lives back on track (Egnew 2009; Le Boutillier et al. 2011; Priebe et al. 2014). Each patient has to discover what their body can tolerate in daily life in order to trust their body again; find out what must be prioritised in their lives; and take actions to adjust their lives to their capabilities. For the patient, this may involve finding out what kind of life is possible to live within the boundaries set by an

illness, restructuring patterns of living, getting used to new habits and routines, and redefining social roles and obligations (Kearney 1999). As in patient-centred practice, this process must be guided by the patient's priorities, values, abilities and competences (Priebe et al. 2014). A person's recovery process is powered by their hope, engagement and strength, and by support and engagement from others. The endpoint of this recovery process cannot be predetermined, but is part of the patient's explorative learning process. The path to recovery may take different turns over time, and a relapse does not necessarily have to be interpreted as a failure but rather as something that gives new insights. Thus, a personal recovery process, as illustrated by the person-oriented evidence from interviews of patients with FM, communicates well with a resource-oriented recovery model and the clinicians' efforts to engage in delivering patient-centred practice.

Underpinning the new rehabilitation programme is an assumption that although wellness can be over-shadowed by illness, it is not inevitably lost because of it. A patient therefore is believed to have the capacity to re-shape their future and bring wellness back to the fore (Lucey 2017). Learning that FM is a chronic illness that one has to learn to accept and live with can deprive a patient of hope and motivation to overcome FM. However, knowing that someone has recovered can provide hope and empower a patient to take action. But if a patient should fail at their recovery, our discussions highlight the fact that health professionals must be aware that the patient should not be blamed.

## **Final reflections about what we learnt**

By bringing person-oriented evidence from qualitative studies into the process of developing the rehabilitation programme, we created an opportunity for health professionals to express otherwise personal clinical experiences and discuss them with others. The reflections were

facilitated by discussions across qualitative studies and clinical experiences, as well as the researchers' explorative approach in accordance with qualitative research. We actively used theories about personal suffering and healing to interpret the group's reflections, thereby introducing new interpretations to the group. This ended up becoming a fruitful discovery process for us all. Moreover, the gap between clinical experiences, evidence and patient-centeredness was bridged with the help of biopsychosocial and personal resource-oriented models. Thus, we argue that by taking a 'bottom-up' approach, we were able to develop a theory-driven and patient-centred rehabilitation programme that also includes clinical experiences and preferences.

The prior rehabilitation programme aimed to promote a healthy lifestyle among patients to improve health. The new programme is more focused, as it targets life stress modifications which is linked to an understanding of the FM condition. Certainly, healthy lifestyles can impact life stress, and it may still be relevant to bring in elements from exercise, pain modulating techniques and diets. But the difference here is that the purpose of the programme has changed, and this may in turn change the ways strategies are applied. For example, physical activity can serve as a strategy to modulate stress instead of previously to improve physical fitness. Instead of choosing strategies from a 'tool-box' of health strategies, the new programme has no tool-box, rather each patient has to find what is right for them to do to modify their life stress and overcome problems of FM.

In patient-centred practice it is important to acknowledge the patient's experiences, and we argue that it is also important to understand the meaning of what patients say by taking into account patients' experiences during the programme. Patient-oriented evidence can enable clinicians to make sense of and respond to patients' stories. For years, this has been emphasised

by physicians practicing narrative medicine, for example Clark and Mishler (1992) and Kleinman (1988). Despite the fact that patient-centeredness is included in the EBP model, qualitative studies have not been suggested for the sake of understanding experiences. However, we learnt that qualitative studies are important for interpreting both patients' and professionals' experiences. Thus, we suggest that qualitative studies should be brought into the field of rehabilitation to support patient-centred practice.

In summary, with the help of theoretical models and interpretations, qualitative studies and qualitative explorative interviews and analysis, the content of a theory-driven, patient-centred rehabilitation programme was developed. As the health professionals were actively engaged in the development process, they created an ownership of the programme. Thereby, the programme was directly implementable to practice. New concepts and ways of talking about a patient's recovery process are now being used by the health professionals: for example, they refer to turning points, small and big steps towards change, patients' discoveries, and healing work in context of everyday work, biographical and identity work. This does not mean that all clinical uncertainties and dilemmas are answered, but they can be articulated and discussed by the team in light of theoretical knowledge about FM, illness and the patients' personal recovery processes.

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# Nytt rehabiliteringstilbud til pasienter med fibromyalgi



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**Intervjuer med kvinner** som er blitt friske av fibromyalgi (FM) har lært artikkelforfatter mye om personlige tilfriskningsprosesser. Gjennom møysommelig prøving og feiling har tidligere pasientene på egenhånd lært seg hva slags liv de tåler å leve og klart å bygge opp igjen meningsfulle liv.

I løpet av prosessen har de blitt symptomfrie.<sup>1-5</sup> De har verken funnet en «vidundermedisin» eller deltatt i behandlinger etter EULARs kliniske retningslinjer, hvor det anbefales pasientundervisning og trening.<sup>6</sup> Tilfriskningen har vært en ensom prosess og resultat av deres egen innsats. Veien mot tilfriskning har ikke vært rett fram, og ikke har de gått den samme veien. Men de har gått fra en situasjon hvor uforutsigbare symptomer har kontrollert hverdagslivet, til en situasjon hvor de selv etter hvert har tatt tilbake styringen.

Mange tilpasninger i livet er blitt gjort underveis, og de lever på en annen måte i dag enn de gjorde før de ble syke. Men de tåler betydelig mer nå enn det de gjorde da de var syke, og de er tilbake i arbeid. Og, ikke minst – de er symptomfrie og fornøyd med livene de lever i dag.

Selv om mine kollegaer og jeg har lært mye av å intervju tidligere pasienter, er det dessverre ikke

slik at vi sitter på en oppskrift på hvordan pasienter med FM skal bli friske igjen. Det er usikkert om det tidligere pasienter har gjort er årsak til at de er blitt symptomfrie. Videre er det usikkert om funnene kan omsettes til klinisk praksis. Imidlertid syntes vi at det var verdt å forsøke.

Med to års økonomisk støtte fra Extrastiftelsen Helse og Rehabilitering satte jeg høsten 2017 igang et prosjekt i samarbeid med et tverrfaglig rehabiliteringsteam ved Revmatismesykehuset på Lillehammer (LRS). Her vil jeg presentere hvordan det tverrfaglige teamet ved LRS, en postdoktor og jeg (fra Universitetet i Oslo) har arbeidet med å utvikle og prøve ut et nytt tverrfaglig rehabiliteringstilbud for pasienter med FM.

## Refleksjoner på tvers av ulike tankesett

LRS har i mange år tilbudt et tverrfaglig gruppebasert rehabiliteringsopplegg til pasienter med FM, bl.a. som en del av «Raskere tilbake»-satsningen. Tilbudet har fokusert på å informere pasientene om FM, undervise i strategier for å mestre FM og gjøre livsstilsendringer, f.eks. med tanke på kosthold og trening. De ansatte ved LRS har således mye klinisk erfaring og kompetanse når det gjelder å arbeide i tråd med EULARs anbefalinger.<sup>6</sup> Anbefalingene legger imidlertid til grunn et annet tankesett enn forsk-

ning om pasienters tilfriskningserfaring. Å reflektere på tvers av ulike tankesett ble dermed sett på som en mulighet til å få til noe nytt.

### Utviklingsprosessen

Et tverrfaglig team bestående av leger, ergoterapeuter, fysioterapeuter, dietetiker, psykolog, sosionomer, sykepleiere og administrativ leder deltok på 5 dags-seminarer i perioden september 2017 til januar 2018. Postdoktor arbeider i sin forskning med pasienters erfaringer med å leve med FM, men kunne også stille spørsmål ved det som ble tatt for gitt av oss nordmenn, da hun er finsk og kjenner lite til norsk rehabiliteringskontekst. Jeg kjente teamet fra før, da jeg har en bistilling ved LRS, men visste relativt lite om det eksisterende rehabiliteringstilbudet.

I forkant av seminarene sendte jeg ut 2-3 vitenskapelige artikler som omhandlet pasienters erfaringer med å få diagnosen FM, leve med den, møte helsepersonell og å komme seg igjen. Artikkene viste seg å sette i gang refleksjoner rundt egne kliniske erfaringer. Det som ble sagt på seminarene, ble enten tatt opp på bånd eller skrevet ned som feltnotater umiddelbart etterpå. Forskerne oppsummerte det som ble sagt og presenterte det på neste seminardag. Dette ble gjort for å validere våre fortolkninger, skape kontinuitet i arbeidsprosessen og for til slutt å kunne skrive fram et teoretisk begrunnet rehabiliteringstilbud. Refleksjonene fortsatte mellom seminarene, og leder ble en viktig driver for å holde utviklingsprosessen i gang.

Det ble diskutert tema som f.eks. FM-diagnosens og pasienters legitimitet, frustrasjon over pasienters manglende motivasjon, syn på normalitet og normalisering, og syn på forventninger og usikkerhet.<sup>7</sup> Gjennom refleksjonene ble det også tydelig at biopsykososial modell hadde betydning for hvordan teamet forstod FM, og det praktiske arbeidet var inspirert av idealer fra pasientsentrert praksis. Imidlertid var det vanskelig å se hvordan innholdet i eksisterende

program hang i hop på en logisk måte. Praksiserfaringene tydeliggjorde også flere dilemmaer helsepersonell står overfor i praksis, f.eks. når det gjelder å hensynta pasienters autonomi når pasienter ikke vil gjøre endringer. Personalet la ansvaret for dette på seg selv ved at de mente at de måtte kommunisere bedre og bli flinkere til å motivere pasientene sine.

### Det nye programmet

Hensikten med det nye programmet er å modifisere livs-stress. Livs-stress forstår vi som et begrep som innbefatter alt som tynger et liv, og dersom det blir for mye av det, «renner begeret over».<sup>1</sup> Noen studier antyder at stress kan være utløsende faktor ved FM, men vi har tatt utgangspunkt i at livs-stress forverrer symptomer og således kan være en vedlikeholdsfaktor. Teoretisk begrunner vi dette ved å se sammenheng mellom biologiske forandringer (hypersensitivitet i sentralnervesystem og hyporesponsivitet i nevroendokrine systemer) og forverring av plager ved fysiske, mentale og sosiale belastninger.

I programmet blir det dermed viktig at slik sammenheng gjøres forståelig og meningsfull for pasienter, for deretter å kunne bruke forverringer til å oppdage og gjøre noe med unødvendige belastninger i eget liv. Helsepersonells oppgave blir å stimulere den enkelte pasient til å utforske egen situasjon, og gi råd og støtte i forhold til å gjøre endringer i livet slik at livs-stress modifiseres.

Helsepersonellet samarbeider på denne måten om en felles hensikt, dvs. å modifisere livs-stress og dermed gjøre hverdager mer forutsigbare. Men pedagogisk tilnærming i form av undervisning, erfaringsdeling mellom pasienter og veiledning i grupper er den samme som før. Mye av det tidligere innholdet er beholdt, men det er nå justert slik at det henger sammen med den overordnede målsetningen om modifisering av livs-stress. For eksempel er fokus på trening og bedret fysisk kapasitet nå blitt endret til fokus på fysisk aktivitet for å modifisere stress.



## Implementering

Siden februar 2018 har det nye opplegget blitt tilbudt pasienter med FM som er henvist til «Raskere tilbake»-tilbudet ved LRS. Til nå har tre grupper gjennomført programmet. Pasientene (10-12 stykker) deltar i et poliklinisk gruppetilbud på 8 hele dager som strekker seg over tid. Både pasienter og helsepersonell er ganske samstemte om at temaene og måten det arbeides på gir mening. Det er gjort mindre praktiske justeringer underveis som følge av pasienters og helsepersonells erfaringer, f.eks. er kursdagene forkortet.

Innen implementering snakker en gjerne om å overføre kunnskap fra forskning til klinisk praksis (kunnskapstranslasjon), og denne kunnskapsoverføringen går gjerne én vei. Vi har imidlertid reflektert på kryss og tvers av kliniske erfaringer og forskningskunnskap for å utvikle ny innsikt sammen.<sup>8</sup> I tillegg til at vi alle har lært noe gjennom arbeidet, har alle fått eierskap til det nye rehabiliteringsopplegget.

## Nytte for personale og pasienter

Etter ca. ett års erfaring med å arbeide i det nye programmet har alle i rehabiliteringsteamet blitt intervjuet. Generelt viser det seg at personalet er fornøyd med å arbeide med det nye tilbudet og at de føler seg styrket som fagpersoner gjennom å ha deltatt i utvikling av og samarbeidet om gjennomføring av det nye programmet.

Mens tilbudet før i stor grad var formet av fagprofesjoners tradisjoner, fremheves det som betyd-

ningsfullt at de ulike fagprofesjonene i dag kan se sitt faglige bidrag inn i en større sammenheng. Det felles anliggende gjør at det blir relevant å diskutere egne erfaringer med de andre i teamet. Samarbeid og støtte fra kollegaer gir faglig trygghet, påfyll og videreutvikling. Selvfølgelig er ikke klinisk praksis blitt «rosenrød» – vanskelige problemstillinger dukker opp og drøftes i teamet.

Når det gjelder evaluering av pasienters utbytte så pågår dette arbeidet, og datainnsamling avsluttes desember 2019. Det antas at det vil ta tid før pasienter har fått gjort endringer som fører til at de får det bedre, og vi følger dem derfor opp etter ca. ett år. Evaluering skjer på både gruppe- og individnivå. Det undersøkes om gruppen er blitt bedre av FM ved hjelp av standardiserte spørreskjema. Hvorvidt den enkelte har blitt bedre undersøkes ved hjelp av kvalitative intervju, for å få vite hva som har skjedd over tid, hva som har fått betydning og om de forteller om fremgang.

## KONKLUSJON

Dette prosjektet har fulgt struktur for utvikling av komplekse intervensjoner, og vi er nå i «feasibility» og piloteringsfase.<sup>9</sup> Det er for tidlig å si om dette prosjektet bør videreføres som et større prosjekt og etter hvert eventuelt bli implementert mer generelt. Tilbakemeldinger vi har fått gjør oss optimistiske, men det må mer systematisk oppfølging til.

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# Attestasjon fra budsjettansvarlig leder ved institusjonen

## Prosjekt finansiert av Stiftelsen Dam

Navn på budsjettansvarlig: Knut Tore Stokke

Stilling: Kontorsjef

Institusjon: Institutt for helse og samfunn, UiO

Prosjektnummer: UiO 710171, DAM 2017/HE2-184218

Prosjektnavn: Utvikle intervensjon for fibromyalgi

Søkerorganisasjon: Norske Kvinners Sanitetsforening

Regnskapsperiode \*: Fra dato / år...01.01.2020.....til dato / år...30.09.2020.

Kontrollgrunnlag:

- ❖ Prosjektsøknad med opprinnelig budsjett
- ❖ Stiftelsen Dams rundsummer og forklaring til disse (gjelder kun forskning)
- ❖ Stiftelsen Dams kommentar til bevilgningen
- ❖ Godkjente endringer fra Stiftelsen Dam som påvirker opprinnelig budsjett
- ❖ Regler for regnskapsrapportering på Stiftelsen Dams nettsider

Prosjektregnskapet:

Dette viser påløpte kostnader på kr...1.896.298.....og ubrukte midler på kr...-null-....per dato / år.....30.09.2020.....

Eventuelle presiseringer eller kommentarer:

Innkjøpte tjenester/honorar (645.000) i prosjektregnskap gjelder Revmatismesjukehuset A/S, Lillehammer

Jeg bekrefter herved at regnskapet er kontrollert i henhold til ovennevnte kontrollgrunnlag:

24/5-20  
Sted/dato

Budsjettansvarligs underskrift og stempel (i institusjonen)



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\*Regnskapsperiode for Forskningsprosjekter er et kalenderår

Regnskapsperiode for Helseprosjekter er hele prosjektperioden fra startdato til sluttdato