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**ABILITY IN EVERYDAY ACTIVITIES
AND MORALE AMONG OLDER WOMEN
WITH CHRONIC MUSCULOSKELETAL
PAIN LIVING ALONE**

**A BEHAVIOURAL MEDICINE APPROACH IN
PHYSIOTHERAPY**

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Ability in everyday activities and morale among older women
with chronic musculoskeletal pain living alone
A behavioural medicine approach in physiotherapy
THESIS FOR DOCTORAL DEGREE (Ph.D.)

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Till alla äldre kvinnor som lever med långvarig smärta
och som bor hemma med stöd av hemtjänst liksom till all fantastisk
hemtjänstpersonal som kämpar för att hjälpa och stödja sina vårdtagares
möjlighet till att leva ett självständigt liv med ett gott välbefinnande

ABSTRACT

The overall purpose of this thesis was to utilise a behavioural medicine approach in physiotherapy to study how older women with chronic musculoskeletal pain, who live alone and are dependent on formal care, perceive their everyday lives and to explore how their ability to perform everyday activities and morale could be promoted.

Method: This thesis used a descriptive, correlative design (Study I), a randomised two-group design (Study III) and a qualitative inductive explorative design (Study II and IV).

Participants in Studies I-III: Older women (≥ 65 years) with chronic musculoskeletal pain, who live alone, are able to walk with or without walking aids indoors and are dependent on formal care to manage their everyday lives. *Study IV:* Home help service staff who were involved in study III. **Results:** The results showed that many different factors appeared to have impact on the women's health, everyday activities and morale. The target group of older women seemed to report the same pain-related problems, the same degree of pain-related disability and the same beliefs as those found in previous research on older individuals with chronic pain conditions. Despite their chronic musculoskeletal pain and other health complaints as well as their dependencies on others to manage their everyday lives, the results show how important it was for the women to live at home for as long as possible. A key factor in promoting the ability to perform everyday activities among the women was having a daily rhythm in a supportive environment. Another key factor in this context was the home help service staff, who had a strong will and desire to promote their care recipients' independence and quality of life. Nonetheless, the resource that the staff represent could most likely be utilised in a better way. The behavioural medicine in physiotherapy intervention showed that more support from physiotherapists and home help services staff is needed to enhance the effect of this type of intervention among the target group. Nevertheless, the results imply that this type of intervention may improve levels of physical activity, self-efficacy in relation to exercise and management of everyday life, but further research is needed in larger samples. **Conclusions:** This thesis demonstrates that there are many different factors that seem to affect the women's health, ability in everyday activities and morale. The women describe how their ability in everyday activities can be promoted by performing their everyday activities in a daily rhythm, and home help service staff are a key resource in this context. Moreover, physical activity, self-efficacy in relation to exercise and management of everyday life can be improved by a behavioural medicine-based physiotherapy intervention in the target group. To promote the women's abilities in everyday activities, to improve their morale and, in the end, to enable the target group of women to be "ageing in place" in the best possible way, society and health care professionals may have to pay them special attention.

Keywords: ADL, ageing, biopsychosocial model, community-dwelling, caregiver, care recipient, daily rhythm, formal care, everyday activities, elderly, exercise, female, home help service staff, pain management, pain-related beliefs, pain-related disability, physical activity, self-efficacy, quality of life, well-being

POPULÄRVETENSKAPLIG SAMMANFATTNING

En växande grupp i samhället är äldre ensamboende kvinnor som bor hemma med stöd av hemtjänst. Denna grupp har uppmärksammats av Socialstyrelsen som en skör och sårbar grupp som det saknas forskning om hur deras vardagsliv ser ut.

Ett stort hälsoproblem bland den åldrande befolkningen är smärta och cirka 50-70% av den äldre befolkningen lever med långvarig smärta. Generellt rapporterar fler kvinnor än män, oavsett åldersgrupp, att de lever med smärta. Smärta är inte en normal konsekvens av stigande ålder och är ofta både underrapporterad och underbehandlad. Att leva med långvarig smärta är bland annat förknippat med försämrad sömn, ökad risk för och förekomst av depression, minskad aktivitetsförmåga, undernäring och nedsatt immunförsvar, men även med inskränkt socialt liv på grund av försämrad rörelseförmåga och rörelserädsla, katastroftankar och försämrad livskvalitet. Forskning visar att smärtrelaterade problem är mer förekommande hos kvinnor som lever med långvarig smärta, än hos män som lever med långvarig smärta. Likaså rapporterar äldre kvinnor en sämre livskvalitet i jämförelse med män som lever med långvarig smärta. Att vara äldre, ensamboende och beroende av hjälp i sitt vardagsliv har också visat sig vara förknippat med många av ovan nämnda smärtrelaterade problem och försämrad livskvalitet.

Denna avhandling fokusera på välbefinnande. Högt välbefinnande har visat sig vara förenat med att kunna bo kvar hemma, att inte känna sig ensam, ha socialt stöd och nätverk samt att inte vara deprimerad eller uppleva depressiva symtom. Lågt välbefinnande är associerat med bland annat fysisk ohälsa i kombination med smärta, syn- och hörselnedsättning, nedsatt muskelstyrka och rörelsesvårigheter och i slutändan risk för en för tidig död.

Att leva med långvarig smärta är en multidimensionell upplevelse och måste därför beaktas utifrån ett biopsykosocialt perspektiv. Detta perspektiv består av biologiska, beteendemässiga, sociala och omgivande faktorer som är involverade med varandra i en ömsesidig process. Ett av de viktigaste målen avseende vård och rehabilitering av äldre är att ge dem möjlighet att bibehålla och förbättra sin aktivitetsförmåga. Att kunna utföra vardagsaktiviteter av olika slag har visat sig vara fundamentalt för att främja oberoende och livskvalitet hos äldre människor och specifikt för dem som lever med långvarig smärta. Förlust av aktivitetsförmåga är starkt förknippat med ökat vårdbehov, vilket i sin tur kan leda till behov av flytt till äldreboende samt ökad risk för tidig död.

En av svensk välfärdspolitikens grundstenar är kvarboendepincipen och ett begrepp som växt sig allt starkare inom dagens äldreforskning i detta sammanhang är ”aging in place” vilket kan definieras som ”äldre människors förmåga att leva i sitt eget hem, oavsett var det kan vara, så länge man känner sig trygg och bekväm”. Både Socialtjänstlagen, Världshälsoorganisationen och Europeiska Unionen deklarerar att äldre människor ska ha möjlighet att leva ett så aktivt liv som möjligt och få den hjälp och det stöd individen är behov av för att leva ett gott och meningsfullt liv.

Ett sätt att förbättra aktivitetsförmåga hos åtminstone personer i yrkesverksam ålder som lever med olika långvariga smärttillstånd är beteendemedicinska tillämpningar i fysioterapi. Beteendemedicin kan definieras som det tvärvetenskapliga området där kunskap kring psykosociala, beteenderelaterade och biomedicinska frågor relevanta för utveckling av hälsa och sjukdom integreras. Beteendemedicinska åtgärder bygger på att patientens tankar och omgivning har betydelse för rehabiliteringen. Beteendepåverkande åtgärder kombineras ofta med fysisk aktivitet eller träning. Beteendemedicinska åtgärder har visat sig ha positiva effekter på olika smärttillstånd hos personer i arbetsför ålder. Exempelvis har det visat sig att utsträckt över fem år är fysisk träning kombinerat med problemlösningsstrategier, positiv förstärkning, skriftligt behandlingskontrakt och träningsdagbok mer effektivt avseende aktivitetsförmåga, smärtintensitet och arbetsförmåga jämfört med enbart fysisk träning. Studier har också visat positiv effekt av beteendemedicinska åtgärder avseende tro på sin förmåga i specifika situationer (self-efficacy), rörelserädsla och oro. I dag är kunskapen kring beteendemedicinska åtgärder för äldre personer med långvariga smärttillstånd bristfällig.

Att vara äldre, bo ensam, leva med långvarig smärta och vara beroende av andra ställer höga krav på individen att hantera vardagen. Denna avhandling är troligen den första som utifrån ett beteendemedicinskt perspektiv i fysioterapi fokuserar på just denna växande grupp av äldre kvinnor.

Avhandlingens **övergripande syfte** var att studera hur äldre ensamboende kvinnor i ordinärt boende, med långvarig muskuloskeletal smärta, beroende av hemtjänst, uppfattar sitt vardagsliv med långvarig smärta, samt ta reda på hur deras aktivitetsförmåga och välbefinnande kan främjas.

Metod: För att besvara syftet med avhandlingen användes både kvantitativa och kvalitativa forskningsmetoder. Delstudie I bestod av en kartlägningsstudie för att beskriva hur kvinnorna uppfattade sin smärta ur olika dimensioner, hur de skattade sin aktivitetsförmåga och sitt välbefinnande, samt hur sambandet såg ut mellan till exempel aktivitetsförmåga, rörelserädsla, smärtrelaterade katastroftankar och fysisk aktivitet, aktivitetsbegränsningar och välbefinnande. Delstudie II var en intervjustudie med kvinnorna för att undersöka hur de beskrev sin aktivitetsförmåga och vad som kunde främja den. Delstudie III var en pilotstudie som undersökte hur genomförbar en beteendemedicinsk behandling i fysioterapi var för den aktuella målgruppen. Delstudie IV var en fokusgruppintervjustudie med hemtjänstpersonal för att undersöka hur de såg på sin roll att främja aktivitetsförmåga hos den aktuella målgruppen.

Deltagare i studie I-III var äldre ensamboende kvinnor, ≥ 65 år som haft muskuloskeletal smärta sedan minst tre månader, var beroende av hemtjänst minst en gång i veckan med personlig omvårdnad eller hushållsgöromål, som kunde gå inomhus med eller utan gånghjälpmedel, förstod och talade svenska samt hade tillräcklig kognitiv förmåga för att delta i studierna. *Deltagarna i studie IV* var hemtjänstpersonal som delaktiga i delstudie III och som förstod och talade svenska.

Resultat: Resultatet visade att kvinnorna hade levt länge med sin smärta och att den påverkade deras hälsa, vardagsliv och upplevelse av välbefinnande i en negativ riktning. Det visade sig att kvinnorna skattade låg grad av emotionell påverkan, katastroftankar och tilltro till sin egen förmåga i förhållande till utförande av olika vardagsaktiviteter, hög grad av rörelserädsla och lågt välbefinnande. De rapporterade en låg nivå av fysisk aktivitet, men flertalet av kvinnorna hade en önskan om att öka sin fysiska aktivitetsnivå. Även om kvinnorna rapporterade låg grad katastroftankar så var detta den enskilda faktor som visade sig ha samband med både smärtrelaterade aktivitetsbegränsningar och välbefinnande.

Kvinnorna beskrev att de hade en stark vilja att kunna bo kvar hemma så länge som möjligt. Likaså hade de en stark vilja att få vara oberoende i så stor utsträckning som möjligt. Kvinnorna beskrev hur utförande av vardagsaktiviteter i en daglig rytm såsom att klara av att sköta sin hygien, utföra sina fritidsintressen, umgås med familj och vänner, vara ute i naturen och ha stöd från närstående, hemtjänst och frivilligorganisationer stärkte såväl deras fysiska som mentala hälsa. Likaså upplevde de att deras känsla av oberoende blev stärkt genom att använda sig av en daglig rytm i en stödjande miljö. Icke desto mindre efterfrågade kvinnorna att få möjlighet till mer stöd för att kunna vara än mer delaktiga i sitt vardagsliv. De efterfrågade också möjligheten att få mer tillgång till utförande av sjukvårdsinsatser och rehabilitering i hemmet.

Kvinnorna beskrev hur hemtjänstpersonalen både hjälpte och stälpte deras möjlighet till att vara så oberoende som möjligt. Faktorer som påverkade enligt kvinnorna påverkade oberoende var kontinuitet bland personalen, tidsaspekten och att de upplevde att systemet var oflexibelt. En kvinna beskrev hur hon en dag skulle ha hjälp med dusch men inte orkade just då och frågade om hon kunde få komma ut på en promenad med rullstolen, men det gick inte för det var ju inte ”promenaddag”.

Upplevelsen av att både hjälpa och stälpa delades också av hemtjänstpersonalen, men resultaten från intervjuerna med dem visade att personalen tyckte det är oerhört viktigt att främja sina vårdtagares aktivitetsförmåga. De beskrev att de ser sig själva stå i första ledet för att både stärka självkänsla, tilltro till sin egen förmåga, oberoende och i slutändan även livskvalitet hos vårdtagarna. De såg sig själva som ”självhjälpare”, ”motivatorer” och ”kommunikatörer”. De kämpade för vårdtagarnas möjlighet till oberoende, men påverkades av olika faktorer, såsom att förhålla sig till den tid de har fått avsatt för att utföra sitt arbete hos vårdtagaren, vårdtagarens och/eller anhörigas vilja, förändringsbenägenhet och önskemål samt hemmiljöns utformning. Resultatet påvisade också att hemtjänstpersonalens kompetens och kunskap inte tas till vara på bästa sätt. Likaså visades att deras roll skulle kunna optimeras genom ett till exempel förbättrat teamarbete, men framförallt genom att ha mer tid i mötet med vårdtagaren.

En av hörnstenarna i denna avhandling var att utveckla och undersöka hur en intervention baserad på beteendemedicinska tillämpningar i fysioterapi fungerade för den aktuella målgruppen. Resultatet från pilotstudien visade att det behövs mer stöd från fysioterapeut, men kanske även från hemtjänstpersonal, för att genomföra denna typ av behandling. De

problem som identifierades var att en del kvinnor hade svårt att fylla i aktivitetsdagböckerna på grund av till exempel nedsatt syn eller svårt att hålla i penna och detta skulle eventuellt hemtjänstpersonalen kunna hjälpa till med. För de kvinnor som deltog i de beteendemedicinska åtgärderna var det ibland svårt att hitta ett behandlingsmål och det var svårt för dem att utföra balansträning på rätt nivå då de skulle klara av sin träning själva. Inga effekter kunde ses avseende smärtrelaterade begränsningar eller välbefinnande. Dock antyder resultaten att behandlingen kan förbättra tilltro till sin egen förmåga i relation till utförande av träning och förbättra graden av fysisk aktivitet hos de personer som deltog i träningsgruppen och några av deltagarna rapporterade att de kunde hantera sitt vardagsliv bättre efter deltagande i studien.

Slutsatser: Resultaten från denna avhandling har fyllt några av de kunskapsluckor som uppmärksammas avseende hur äldre ensamboende kvinnor som lever med långvarig muskuloskeletal smärta uppfattar att leva med sin smärta, samt hur kvinnornas aktivitetsförmåga kan främjas. Resultaten visar att det tycks vara många olika faktorer som påverkar kvinnornas hälsa, vardagsliv och välbefinnande. Att utföra sina vardagsaktiviteter i en stödjande miljö var en faktor som främjade kvinnornas aktivitetsförmåga och personalen uppfattade att de själva ibland hindrade kvinnornas möjlighet till att få vara självständiga. Pilotstudien indikerade att en behandling baserad på beteendemedicinska tillämpningar i fysioterapi kunde öka kvinnornas fysiska aktivitet, deras tilltro till sin förmåga att utföra träning samt att kunna hantera sitt vardagsliv bättre. Resultaten pekar också på att dessa kvinnors möjlighet till att kunna bo kvar hemma med ett gott välbefinnande kan förbättras. Slutligen indikerar resultatet från denna avhandling att denna specifika målgrupp av äldre människor troligen är en grupp som behöver uppmärksammas i högre grad av samhället och hälso- och sjukvården.

Nyckelord: ADL, biopsykosocial modell, daglig rytm, fysisk aktivitet, hemtjänstpersonal, kvinna, livskvalitet, self-efficacy, sköra, sårbara, smärthantering, smärtrelaterade begränsningar, smärtrelaterade tankar, träning, vardagsaktiviteter, vårdare, välbefinnande, åldrande, äldre.

LIST OF SCIENTIFIC PAPERS

- I. **Cederbom S**, Söderlund A, Denison E, von Heideken Wågert P. Chronic pain among older women living alone. A study focusing on pain-related disability and morale. *European Journal of Physiotherapy*, 2014;16:139-150
- II. **Cederbom S**, von Heideken Wågert P, Söderlund A, Söderbäck M. The importance of a daily rhythm in a supportive environment – promoting ability in activities in everyday life among older women living alone with chronic pain. *Disability and Rehabilitation*, 2014 Feb 12 doi:10.3109/09638288.2014.887795. (Epub ahead of print)
- III. **Cederbom S**, Rydwick E, Söderlund A, Denison E, Frändin K, von Heideken Wågert P. A behavioral medicine intervention for older women living alone with chronic pain – a feasibility study. *Clinical Interventions in Aging*, 2014; 9:1383-1397
- IV. **Cederbom S**, Thunborg C, Denison E, Söderlund A, von Heideken Wågert P. Formal care givers' description of their role to promote everyday activities among older women with chronic pain living alone. *Submitted*

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LIST OF ABBREVIATIONS

ADL	Activities of daily living
CAT	Catastrophizing Subscale
TSK	Tampa Scale of Kinesiophobia
WHO	World Health Organization
CPGQ	Chronic Pain Grade Questionnaire
CSQ	Coping Strategies Questionnaire
EU	European Union
FES-I (S)	Falls Efficacy Scale International, Swedish version
MMSE	Mini Mental State Examination
MPI-S	Multidimensional Pain Inventory, short version
PGCMS	Philadelphia Geriatric Center Morale Scale
PMI	Pain Management Inventory
SCT	Social cognitive theory
SEE-SV	Self-efficacy for Exercise Scale, Swedish version
SES	Self-efficacy Scale
SMART	Specific, Measurable, Activity based, Realistic and Time-delimited
TSK	Tampa Scale of Kinesiophobia
WHO	World Health Organization

PREFACE

My interest in the research field of “being older and in pain” began when I decided to focus on this topic in my master thesis, but the interest derives from my many years as a physiotherapist in the community, active both in long-term and short-term care.

In my everyday practice as a physiotherapist, I met older persons who were in pain, which caused different types of problems, not only for the individual but also for the caregivers who were caring for the older person. I remember an old woman with a hip fracture and confusion, lying in bed suffering from pain, anxiety and fear; the caregiver could not move her or touch her, and the caregivers asked me: “What shall we do, and how can we help her?”. I also met several older persons with chronic pain who expressed that nothing could help them to get any better regarding their physical performance or their ability to perform everyday activities.

Now, a number of years later, with a deeper knowledge and understanding about “being older and in pain” and with this thesis in hand, I think and hope that I am more capable of both supporting older people who live with chronic pain, especially older women who live alone at home, and supporting health care professionals in their everyday practice with this specific group of older people. I also hope that this thesis can make you, as a reader, better able to support and meet older people who live with chronic pain, in your daily work. The goal for all health care professionals is to promote and facilitate these older people’s opportunities to maintain and improve their independence and morale.

1 BACKGROUND

1.1 THEORETICAL FRAMEWORK

The most widely used definition of pain is that given by the International Association for the Study of Pain (IASP): “Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (1). Pain is divided into acute and chronic pain, and chronic pain is mostly defined as “pain that occurs [for] more than three months or until damage is healed” (2). In this thesis, the definition of chronic pain is “pain that occurs more than three months”, and this thesis particularly focuses on chronic musculoskeletal pain.

Pain is a multidimensional experience, and a biopsychosocial approach is important to fully understand how pain experiences affect an individual’s life. This approach is derived from the biopsychosocial model (3), which includes biological, psychological, behavioural, social and environmental factors that are involved with each other in a reciprocal process (4). Based on this model, the interdisciplinary field of behavioural medicine has been derived and can be defined as “the development and integration of behavioural, psychosocial and biomedical knowledge and techniques relevant to the understanding of health and illness, and the application of this knowledge and these techniques to prevention, diagnosis, treatment and rehabilitation” (5).

Physiotherapy as science is based on the biopsychosocial model and can be defined as “services to individuals and populations to develop, maintain and restore maximum movement and functional ability where movement and function are threatened by ageing, injury, pain, diseases, disorders, conditions or environmental factors” (6). During the last decades, physiotherapists have worked on integrating behavioural medicine principles in physiotherapy. The focus has been to support behavioural change in everyday activities by improving the physical, psychological, and organisational skills that are relevant to the prioritised activities, with the ultimate goal being improved participation by persons with chronic musculoskeletal pain (7). The theoretical framework for this thesis is based on a behavioural medicine approach in physiotherapy.

1.2 AN AGEING POPULATION LIVING AT HOME

The most common definition of an older person is ≥ 60 years, but there is no general agreement as to the age at which a person becomes old (8); the present thesis uses ≥ 65 years. The proportion of older people will increase worldwide (9), and Sweden has one of the oldest populations in the world (10). The majority of older people in Sweden as well as in Europe are living alone in ordinary housing, and women comprise the majority of this group (11, 12).

To be old and living alone is associated with poorer health, a higher degree of pain, greater disability with regard to instrumental activities of daily living (I-ADL), functional decline, multiple falls, activity limitations related to a fear of falling and a higher degree of mental illness and depressive symptoms (13-17). Because more women than men live alone, it is of

great interest to know that older women have reduced ADL ability, physical capacity and cognition compared with older men (18-21). Regarding ADL ability, we have chosen to have a broad perspective in this thesis on “everyday activities” and include all types of activities that may occur in an individual’s everyday life. Being able to perform and do everyday activities has shown to be a key factor to managing everyday life with advanced age (22).

The specific group of older people who live alone, and especially older women, has previously been highlighted as a group that needs particular attention from society and health care services (15, 16, 23). The National Board of Health and Welfare in Sweden has described the group of older women who are living alone as a frail and vulnerable group of older people, and there is a lack of research about their life situation (24). Overall, there is a research gap about the life situations for older people who live alone (15).

In Sweden, as in other countries around the world, care is oriented towards care that takes place in ordinary homes with support from the community (12, 25-28). In Sweden, it is fundamental that older people shall be able to live at home as long as possible under good circumstances (25).

The home has been shown to be central and important for older people (29-31). A concept in this field is “ageing in place”, which can be defined as “older people’s ability to live in their one own home, wherever that might be, for as long as one can feel confident and comfortable” (32). Older individuals have described “ageing in place” to improve their independence and autonomy (26). However, to be able to “age in place” may result in profound challenges and demands on the caregivers who support and help these older people (33). In Sweden today, older people who live in ordinary housing have more complex care needs (34) and these needs lead to the work that the home help service staff perform, which is highly qualified medical care (35). According to Swedish law, older people shall be able to live an independent life and have an active and meaningful life together with others in a safe environment. Older people shall also have the help that they might need in their homes (36). The World Health Organization (WHO) and the European Union (EU) have also stated that older people shall have the opportunity to enhance independence and quality of life as they age. They shall also have the opportunity to participate in society according to their needs, desires and capacities while being provided with adequate protection, security and care when they require assistance (37, 38). In Sweden, the municipalities have the responsibility to care for the old (36), and 24% of all older people older than 80 years receive some kind of support from the municipality (39). The help from the municipality is defined as “formal care”, with “informal” care referring to help from relatives.

There is a higher percentage of older women than men who are dependent on formal care (12), and the amount of formal care increases with the degree of ADL disabilities (21). Common problems for older people receiving formal care include chronic pain, impaired mobility and depression, which are more common among women (12, 40). Additionally, there is a negative relationship between quality of life and both living alone and the number of health complaints among older people who are dependent on formal and/or informal care

(40). An important goal during the care of older people is to maintain their ability to perform everyday activities (21). These activities are of importance for maintaining older individuals' independency and quality of life (22, 41, 42). Loss of the ability to perform everyday activities has been shown to have a strong association with institutionalisation, caregiver burden, higher resource use and death (43-46).

1.3 OLDER PEOPLE AND PAIN-RELATED DISABILITY

Pain is one of the major health problems faced by the ageing population (47, 48). The prevalence of chronic pain among community-dwelling older people, including those who live in ordinary housing and are dependent on formal care, ranges from 45-80 %. Overall, pain is more common among older women than among older men (12, 48-50). Chronic musculoskeletal pain is the most common type of pain in the older population and is more common among women (48, 51). Unfortunately, chronic pain among older people is still under-diagnosed, under-assessed and under-treated (47, 52).

For an older person, living with chronic pain is associated with different pain-related problems such as disability, mobility problems, fatigue, social isolation, sleep disturbances, psychological distress, depression, and a lower quality of life (47, 49, 53, 54). Pain-related problems also seem to be more common among women compared with men who live with chronic pain. Previous research has shown that older women living with chronic pain report lower quality of life compared with men in this context (53, 55). Daily pain is a risk factor for developing pain-related disability (47).

Pain-related disability can be defined as how chronic pain interferes with various daily activities and participation in daily life (56). Pain-related disability is determined by body functions, personal factors (e.g., cognitions and emotions) and the interactions between the individual and the environment (57). A biopsychosocial perspective is necessary to really evaluate and understand how a pain condition can develop into a disabling condition (58).

Among non-disabled community-dwelling older people who are living with musculoskeletal pain, the risk of disability increases with number of areas that are reported to be in pain (59). A newly published study showed that community-dwelling older people living with chronic musculoskeletal pain have a substantially greater risk of developing disability and impaired mobility performance over time (52). Similar results have also been found among older people receiving home care (49).

Previous research has found that widespread musculoskeletal pain predicted worsening difficulty in ADL and mobility disability among older women with disabilities who were not dependent on formal care. No associations between pain-related disability and either depression or anxiety were found in earlier studies (55, 60). However, previous research has shown that there seems to be no differences in the ADL capacity among older people who are dependent on help to manage their everyday life, regardless of whether they are living with or without pain (61).

Knowledge about how community-dwelling older living with chronic musculoskeletal pain experience their everyday life is scarce, and the need for more knowledge is addressed by previous research (48, 62). The need for knowledge is particularly important for community-dwelling older women who are facing higher degrees of pain and its negative consequences compared with older men who live with chronic pain (55, 63).

1.4 MORALE

Morale is often used synonymously with subjective or psychological well-being, quality of life and life satisfaction (64, 65). In the literature, these different concepts are defined, described and used in different ways (66). Morale is a multidimensional concept, and Lawton (67) defined morale as a “basic sense of satisfaction with oneself, a feeling that there is a place in the environment for oneself, and a certain acceptance of what cannot be changed”. This definition of morale has been used in this thesis. Lawton also developed the Philadelphia Geriatric Center Morale Scale (PGCMS) to measure morale (68).

People with high morale are often sociable and active and have an optimistic outlook, but these different personal characteristics are not necessary components of high morale (67). Factors such as living in ordinary housing, having good cognitive function, having a social network and social support, not feeling lonely and lacking depressive symptoms are associated with a high level of morale among the older population (69, 70). Factors that improve morale among older disabled people who are home-bound include motivation, functional capacity, and family support (71).

Low levels of morale have been found to be associated with physical illness in combination with chronic pain, vision and hearing impairments, depression and depressive symptoms, decreased strength and physical mobility and an increased risk of mortality (18,72-75). It seems unclear whether age is related to morale. A population-based study found no differences in morale among those who were 85, 90 or 95 years and older (69). Nevertheless, another study found that people aged 90 years and over had a higher morale compared with those who were between 70-89 years old (76). It is also unclear whether there is a sex difference in morale among the older population (76, 77).

A meta-analysis of 36 studies concluded that exercise and physical activity are positively associated with well-being (78). A high-intensity functional exercise (HIFE) program for older adults living in residential care facilities showed positive short-terms effects on morale (79), but another study did not find any effects on morale in relation to exercise interventions for older adults living in a similar context (80). Knowledge about how the target group of this thesis perceives their morale appears to be scarce, and more knowledge is needed.

1.5 A BEHAVIOURAL MEDICINE APPROACH IN PHYSIOTHERAPY

The behavioural medicine approach in physiotherapy is mainly based on respondent and operant learning theories (81) and social cognitive theory (SCT) (82, 83). In relation to the theories and the aim of this thesis, the concepts of fear avoidance, pain catastrophising thoughts, self-efficacy and self-regulation are more clearly described because they are key concepts in this thesis.

1.5.1 Fear avoidance and pain catastrophising thoughts

Fear avoidance and pain catastrophising are theoretically related to both respondent and operant learning theories. The respondent learning theory addresses how we automatically react in relation to different stimuli and how an originally neutral stimulus can be conditioned to cause a reflex-like behaviour, e.g., avoidance. The operant learning theory describes how our behaviour is controlled by its antecedents and consequences (81).

Fear avoidance in the context of pain can be explained by “the avoidance of movements and activities based on fear” (84). A specific fear in this field is kinesiophobia, which can be described as “fear of movement (re)injury, a specific fear of movement and physical activity that is (wrongfully) assumed to cause injury” (85). Pain catastrophising plays a central role in the development of fear avoidance and can be defined as “an exaggerated negative mental set brought to bear during actual or anticipated painful experience” (86).

Fear of movement and pain catastrophising thoughts have been studied widely among the younger population and are common problems for those who are living with chronic musculoskeletal pain (87, 88). Negative relationships between pain-related beliefs, e.g., pain catastrophising thoughts, and quality of life have also been observed among middle-aged patients with chronic pain (89). Only in recent years has this field focused on older people (90). Keefe et al. (91) showed that there seem to be a sex difference; women who are approaching old age (mean age 61 years) have higher levels of pain-related disability, pain behaviour and pain catastrophising thoughts compared with men who live with chronic musculoskeletal pain.

A common problem among older people in the context of fear of movement is the fear of falling. A previous review showed that nearly 30% of older community-dwelling people fall every year (92). Additionally, older people who live with pain most likely have a greater risk of developing a fear of falling (93). However, the degree of fear of movement and pain catastrophising thoughts and the relationship between these factors and morale have not been studied in the target group.

1.5.2 Social cognitive theory and its concepts self-efficacy and self-regulation

In social cognitive theory (SCT), behaviour is viewed as a dynamic interaction between the individual and the environment, known as reciprocal determinism (83). Moreover, in SCT, the behaviour is driven by beliefs about consequences. An example is how a woman who has developed an avoidance behaviour would reduce physical activity so she does not exacerbate her lower back pain.

A key feature in SCT is self-efficacy, which can be defined as the situation-specific belief in one's ability to successfully perform a particular behaviour (82, 83). Self-efficacy is a crucial factor if a person will implement some form of behavioural changes, e.g., increasing his or her physical activity levels. Self-efficacy beliefs also play an important role in embracing a new behaviour, generalising the new behaviour to other situations and maintaining the altered behaviour over time (83). A low degree of self-efficacy seems to be associated with the maintenance of pain, pain-related disability and depression among older people living with pain (3, 94). The evidence regarding the role that self-efficacy plays in various contexts is broad and includes self-efficacy's positive effect on physical performance, management of psychological aspects of pain and pain-related disability (3, 95).

Self-regulation is another important concept in SCT. It involves a person's ability to control themselves through goal setting, self-monitoring, evaluation and adaptation of behaviour performance and social support. To undertake initiative and maintain behaviour changes, self-regulation is of high importance (96). The use of goal setting has beneficial effects on pain-related disability for chronic pain patients in the primary care setting (97). The ability to take initiative and maintain behavioural changes has been shown to be more complicated for older people, due to, e.g., lack of cognitive capacity or available support (98).

1.5.3 Behavioural medicine in physiotherapy interventions

Being able to perform a movement in a purposeful manner is not determined by physical characteristics alone. It is also determined by cognitive factors, such as beliefs, expectations, and the social and/or physical environment (99). By integrating behavioural medicine and physiotherapy, this strategy utilises aspects of movement as both a physiological phenomenon and a behaviour and provides tools for the systematic support of behavioural changes during treatment (7). Applying a behavioural medicine approach in physiotherapy requires that the physiotherapist and the patient work together systematically to achieve target goals based on the patient's perspective. The target goals should be related to an increased ability to perform activities and problem-solving strategies where the patient is feeling hindered as a consequence of disability or pain (7).

The behavioural medicine approach in physiotherapy is characterised by a systematic consideration of the patient's physiological and psychological conditions and the social and physical environmental factors that are related to the goal for the treatment. A basic idea in the treatment is the individual functional behaviour analysis. This analysis is used to generate hypotheses of the various elements that form the basis for treatment selection. The target

goals are set so that the patient can master the physiological, psychological, organisational and behavioural skills needed to manage the relevant activities and situations in the patient's everyday life. A basic idea behind the treatment is that if a person acquires skills to manage a specific activity, these skills can be systematically generalised to more activities or situations (7).

The basis of treatment in the behavioural medicine approach in physiotherapy is physical activity and exercise (7). Physical activity is defined by the WHO as “any bodily movement produced by skeletal muscles that requires energy expenditure” (100). The American Geriatric Society has clearly stated that physical activity and exercise should be included in the treatment of older people who live with chronic pain (101, 102). The health benefits of being physically active are well established and the benefits are approximately the same for older people as for other age groups (103,104). Physical exercise is an important factor for reducing limitations and participation restrictions among older people living with chronic pain (105). Nevertheless, older people living with chronic pain are less physically active compared with older people living without pain, which can in turn endanger their independence and quality of life (106, 107). Additionally, older people living alone are less physically active compared with those who are living with someone (14), and older women are less physical active than older men (16,108).

A behavioural medicine approach to physiotherapy has been shown to improve the patient's ability to perform everyday activities in middle-aged populations as well as in children and adolescents living with chronic musculoskeletal pain (109-116). This specific treatment approach has also been shown to improve physical activity and facilitate eating behaviour among patients with sleep apnoea (117). The Swedish Council on Health Technology Assessment's report from 2010 recommended that this type of treatment should be incorporated into the treatment of patients with chronic pain in the primary care setting (118). However, there is a lack of studies in the present field that address older people living with chronic pain (119, 120), and evidence-based guidelines for the treatment of chronic pain in community-dwelling older people are emerging (47, 121).

2 RATIONALE

Older women with chronic musculoskeletal pain who live alone at home and are dependent on formal care to manage their everyday lives are a growing group within society. How chronic musculoskeletal pain affects these women's everyday lives has not yet been studied using a behavioural medicine approach in physiotherapy. Additionally, there is a research gap in understanding how pain-related beliefs, ADL function and self-efficacy in activities are associated with pain-related disability and morale. Finally, there is a need to gain knowledge about how health care professionals can help these older women, promote their ability to perform everyday activities and increase their morale.

As far as we know, no one has yet explored this specific research area using a behavioural medicine approach while focusing on this group of older women.

3 AIM

The overall aim of the thesis was, from a behavioural medicine approach in physiotherapy, to study how older women with chronic musculoskeletal pain who live alone and depend on formal care perceive their everyday lives and to explore how their abilities in everyday activities and morale can be promoted.

Study I:

1) To investigate how older women who are living alone with support from home help service perceive chronic musculoskeletal pain, activities of daily living (ADL), physical activity, affective distress, pain-related beliefs, pain management, rate pain-related disability and morale, and (II) to investigate the relationships between demographic variables, ADL, physical activity, affective distress, pain-related beliefs and pain management with pain-related disability and morale.

Study II:

To explore how older women living alone with chronic musculoskeletal pain, describe their ability in performing activities in everyday life and what could promote their ability in activities in everyday life as well as their perceived meaning of a changed ability to perform activities in everyday life.

Study III:

To explore the feasibility and to evaluate an individually tailored integrated behavioural medicine in physiotherapy intervention for older women, living alone at home, having chronic pain and dependent on formal care to manage their everyday life.

Study IV:

To explore how home help service staff describe their role in promoting ability in everyday activities among older women with chronic musculoskeletal pain who live alone at home and are dependent on formal care to manage their everyday lives.

4 METHODS

4.1 DESIGN

To accomplish the overall aim, both quantitative and qualitative methods were used. An overview of the studies is outlined in Table 1.

Table 1. Overview of the design, data collection and analysis, number of participants and time of data collection for studies I-IV

Study	Design	Data collection and analysis	Number of participants	Time of data collection
I	Cross-sectional and correlative design	Interview-administered data collection based on demographic data and questionnaires Descriptive statistics, independent T-test, Spearman's rank correlation, point biserial correlation and standard linear multiple regression analysis	60	Apr. 2010 – Aug. 2011
II	Inductive explorative qualitative design	Qualitative interviews analysed with inductive content analysis	12	Sept. 2011 – Jan. 2012
III	Randomised two-group design	A 12-week intervention with pre, post and 12-week follow up Descriptive statistics, independent T-test, Mann-Whitney U test, Wilcoxon signed rank test and field notes	23	Feb. 2013 – Mar. 2014
IV	Inductive explorative qualitative design	Focus group interviews analysed with thematic content analysis	12	Jan. – Feb. 2014

4.2 PARTICIPANTS AND SETTING

All four studies were conducted in the context of community-dwelling older women living in the central part of a medium-sized municipality in Sweden.

4.2.1 Studies I-III

All women who were aged ≥ 65 years, living alone in ordinary housing and dependent on home help services at least once a week for individual care and/or housekeeping activities were invited to participate. The names and addresses of the participants were collected from a data registry for the municipality. In addition, the following criteria were checked during recruitment:

- the presence of musculoskeletal pain for three month or longer;
- the ability to walk independently indoors, with or without a walking aid;
- the ability to understand and speak Swedish; and
- a score of 24 points or more on the Mini Mental State Examination (MMSE) (122).

Participants for study II were recruited from study I. Purposive and strategic sampling was used to obtain patients with a variety of ages and numbers of years living with pain as well as varying support needs, including whether help was needed to go outdoors. In the end, twelve women from study I participated in study II.

Exclusion criteria for study III were as follows: women who regularly visited a physiotherapist and had ongoing physiotherapy treatment for injury/illness, were in a palliative stage of treatment, or had experienced heart failure in the past three months.

Because study III was a feasibility study, a maximum of 30 participants were to be recruited. The first participants who were recruited to study III were those who participated in study I. However, the initial recruitment was not sufficient because only ten women agreed to participate and therefore, further recruitment efforts were made (n=188). Ultimately, three women participated in studies I-III, and seven women participated in both studies I and II. For further information about participation, see Figure 1.

4.2.2 Study IV

Study IV consisted of home help service staff, and the study was based on a purposive sample. Inclusion criteria required that the participants had been involved in the intervention in study III and were able to understand and speak Swedish. In total, twelve home help service staff participated.

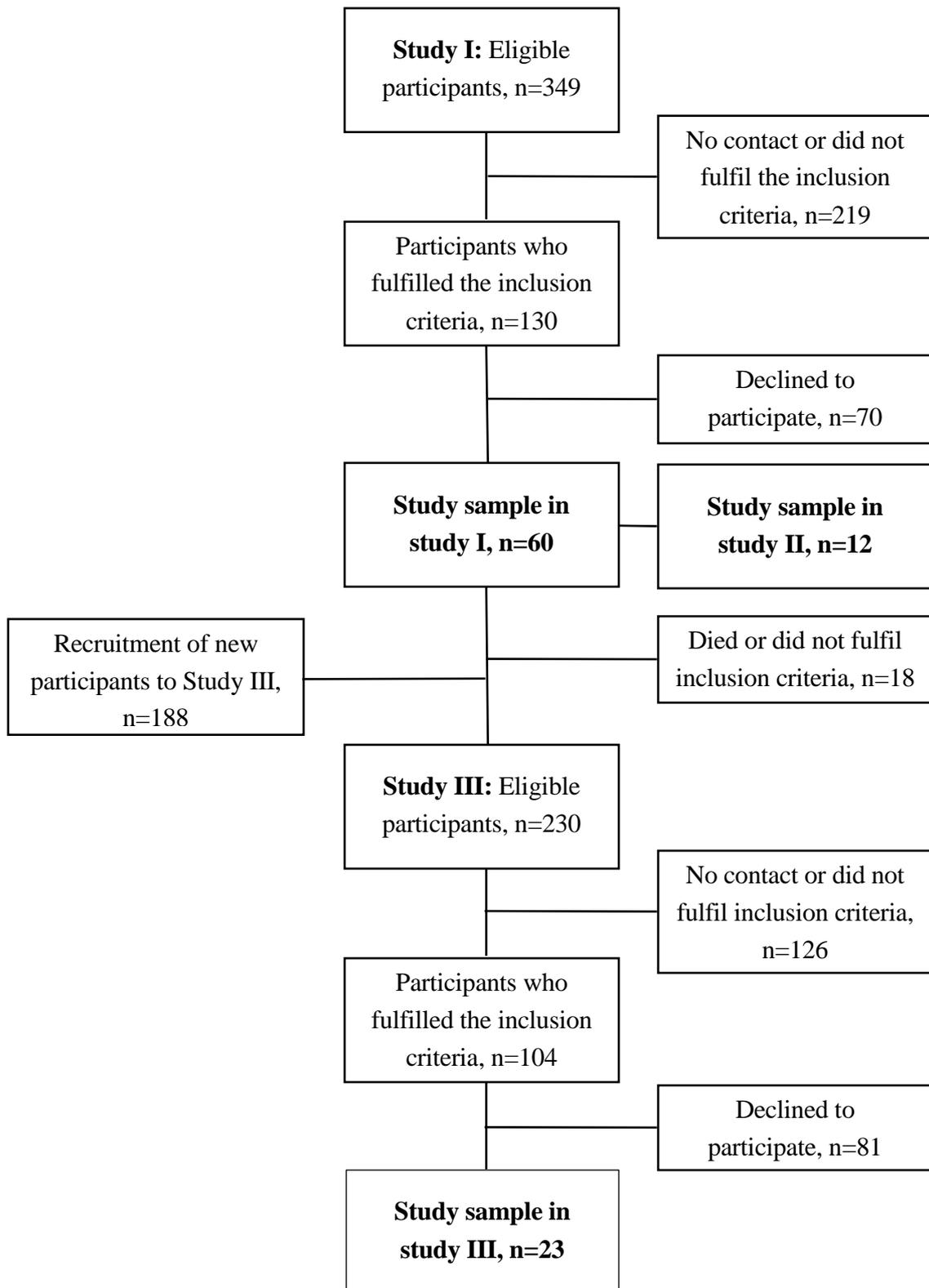


Figure 1. Schematic overview of participant recruitment for studies I-III

4.3 PROCEDURE AND DATA COLLECTION

4.3.1 Study I

At first, all home help service groups and their heads or chiefs received oral and written information about the study, in case they received any questions from the women or their relatives. All women were contacted and informed of the study using a letter and a telephone call a week later. If a woman gave her informed consent, all inclusion criteria were checked over the phone, except for the MMSE score, and an appointment was made for the interview.

Before the interview started, the MMSE score was checked. If the woman had a score of 24 or more, the interview continued; if not, the woman received both oral and written information that her participation in the study was finished due to the low score on the MMSE.

Demographic data regarding living conditions, education, number of years living with chronic pain, pain location, social networks, support from relatives, physical activity, sleep quality, medical status and the use of prescribed medication were collected using questions that were constructed for this study. Demographic data and all questionnaires regarding dependency in ADL, pain severity, pain-related affective distress and beliefs, pain management, pain-related disability and morale were administered in an interview format and conducted in a standardised way; thus, all questionnaires were asked in the same order for all participants. All interviews were conducted in the women's homes, except for two interviews, which were conducted over the phone: one participant did not want to have any visitors in her home, whereas the other participant was difficult to schedule for an interview. The questionnaires that were used are described in a separate section below (see section 5.3.5 and Table 3). Each visit took approximately 1.5 hours.

4.3.2 Study II

Study II was a qualitative interview study. Due to inclusion criteria, ten women from study I were first contacted with a letter that included information about the study and an invitation to participate. Then, each woman who consented to participate was contacted by phone. Two of the interviews were rather short and did not reach a sufficient depth, therefore, two additional women were recruited. In the end, the study consisted of twelve participants.

An interview guide with open questions relating to the aim was used in this study. The main questions were as follows: "What are you doing, how do you perform your everyday activities?" and "What do you think could help you or facilitate your everyday activities?" To provide further details about their experiences, complementary questions were asked, such as "Could you please tell me more about that?" and "What do you think about that?" (123). The interviews lasted between 35 and 90 minutes and were conducted by the first author. The interviews were audio recorded, and the recordings were transcribed verbatim. All interviews were conducted in the women's homes.

4.3.3 Study III

In this feasibility study, the same procedure, using an informative letter and an inclusion criteria check, was followed as described for study I. If a woman fell within the target MMSE scores, the baseline assessment continued; if not, the same procedure regarding low scores on the MMSE was followed as in study I.

The feasibility of the study procedure and the intervention protocol were recorded using field notes during the intervention. The field notes included comments about the time needed to collect the data, adherence to the study procedure and intervention protocol, issues that were recognised in relation to the study procedure and intervention protocols. Consumer questions were asked to assess how satisfied the women had been with the intervention, how they would rate their physical activity level, how they perceived their ability to manage their everyday life after participation in the study and whether they felt they had learned anything during the intervention.

All assessments were made at baseline, follow-up 1 and follow-up 2, except for the consumer questions regarding how satisfied participants had been with the intervention, which was assessed only at follow-up 1. Primary effect outcomes for the study were pain-related disability and morale. Secondary effect outcomes were pain-related affective distress; pain-related beliefs, which consisted of ratings of pain catastrophising thoughts, control over pain and the ability to decrease pain; fall efficacy; self-efficacy for exercise; level of physical activity; the 30-second chair stand test; and the 2.4-meter gait test.

4.3.3.1 *The interventions*

The interventions consisted of a pre-assessment, a post-assessment and a 12-week follow-up assessment. The participants were either randomised to the experimental group, which consisted of an individually tailored integrated behavioural medicine in physiotherapy intervention or to the comparison group, which consisted of general advice about physical activity. During the intervention period, both groups received eight visits by the physiotherapist (first author) during intervention weeks 1, 2, 3, 4, 6, 8, 10 and 12.

Both groups received general advice about physical activity during the first visit based on recommendations for physical activity for older persons, defined as 65 years and over, from the WHO (124) and the American College of Sports Medicine (125). The advice was to be physically active, for example, to take a walk for at least 30 minutes a day, which could be divided into 10-minute sessions. The advice also included examples of different types of activities, e.g., walking both indoors and outdoors, chair stand exercises, balance training, stair climbing and sit-ups. The women also received information about the known benefits of physical activity in relation to pain problems and activity (101, 124, 125). Adherence to the recommendation of physical activity was defined as the women being physically active for at least 30 minutes for five of seven days. Adherence was monitored using an activity diary. The participants were instructed to fill in all physical activities they performed every day as well as the duration and intensity of each activity.

In addition to the general advice about physical activity, the participants in the experimental group received an individualised behavioural medicine in physiotherapy intervention (7, 97, 126). A basic component of the intervention is to identify a problematic everyday activity and identify factors that can be important for the activity, including physical, psychological and environmental factors. The chosen activity is called the “goal behaviour”.

As an example, a goal behaviour in this study could be to be able to walk without a walking aid from the apartment to the lunch restaurant at least two days per week, to be able to stand up and dish up one plate each time or to be able to stand without physical support for at least seven minutes. According to the goal behaviour, the women received different types of exercises that they were instructed to practice at least five of seven days. The content of the intervention is described in Table 2.

The participants in the experimental group were reminded by the home help service staff to do their exercise(s) and fill out the activity diary, with the goal of reinforcing the desired behaviour. The staff received oral and written information about the aim of the reminder and instructions on what they should say. They were then reminded by phone once a week during the intervention period by the physiotherapist. The women were reminded once a day or as often as the women had help from the home help services. The reminder was registered in a diary that was kept in each participant’s home. The goal was to attain at least 80% of the possible reminders from the home help services.

The visits for the comparison group consisted of written and oral information about the general advice regarding physical activity at the first visit. The remaining visits were made to collect and leave a new diary. No exercise advice-related discussions occurred.

Table 2: Description of the intervention for the experimental group

Visit	Intervention component	Contents
1	Identification of a problematic everyday activity. Choice of goal behaviour.	Observation of the performance of the goal behaviour. Identification of physical, psychological and environmental factors that are important for the goal behaviour. Identification of short- and long-term consequences the woman perceived from the behaviour.
	Advice about physical activity	Oral and written information about the advice and instructions on how to fill in the activity diary.
2	Individual Functional Behavioural Analysis	Summary and analysis of collected information. Formulation of hypotheses regarding the relations between the physical, psychological, and environmental factors; the goal behaviour; and the consequences of the goal behaviour.
	Specific, Measurable, Activity based, Realistic and Time-delimited (SMART) goal setting and intervention planning	Discussion and agreement about performance and dosage of training according to SMART goal setting.
3 -5	Basic skills acquisition	Training in the basic physical, psychological and organisational skills relevant to the goal behaviour.
6-8	Applied skills acquisition	Training to apply basic skills adequately for the goal behaviour.
	Generalisation	Application of basic and applied skills to other behaviours, starting with subsequent activity goals.
	Maintenance and relapse prevention	Discussion about how the woman could be able to maintain her new behaviour. Discussion of problem-solving strategies, how she could prevent and address new activity problems that may arise related to the goal behaviour and in relation to being physically active.

4.3.4 Questionnaires and physical tests in studies I-III

All measurements that were used in studies I-III are presented below, and an overview is presented in Table 3. For those measurements that have never been used or are only used in a small extension in the older population, Cronbach's alpha analysis is presented.

Table 3. Overview of the questionnaires and physical tests used in studies I-III

Questionnaires	Study I	Study II	Study III
Pain-related disability: Chronic Pain Grade Questionnaire, CPGQ	X	X	X
Pain severity: Multidimensional Pain Inventory, brief Swedish version, MPI-S	X		
Pain-related affective distress: Multidimensional Pain Inventory, brief Swedish version, MPI-S	X		X
Pain-related beliefs:			
Catastrophising thoughts, Catastrophizing Subscale (CAT) from the Coping Strategies Questionnaire, CSQ	X		X
Two independent questions from CSQ:			
Ability to decrease pain, control over pain	X		X
Fear of movement (re)-injury, Tampa Scale of Kinesiophobia, TSK	X		
Pain management: Pain Management Inventory, PMI			
	X		
Morale: Philadelphia Geriatric Center Morale Scale, PGCMS			
	X	X	X
Self-efficacy beliefs:			
Self-efficacy in activities, SES	X		
Self-efficacy for exercise, SEE-SV			X
Falls Efficacy Scale, International Swedish version, FES-I(S)			X
Dependency in ADL: ADL staircase			
	X		
Level of physical activity and physical tests:			
Estimated for the summer and winter seasons according to a six-grade scale, the 2.4-meter gait test and the 30-second chair stand test			X

Pain-related disability

Pain-related disability was assessed using a slightly modified Swedish version of the Chronic Pain Grade Questionnaire (CPGQ) (127). In the original version (128), the questions assess pain-related disability during the past six months; in this modified version, pain-related disability was assessed during the past four weeks (129). The CPGQ consists of seven items. Six of the questions have an 11-grade response format. The first three items rate pain intensity, where the response format is 0=no pain and 10=worst imaginable pain, which is based on a calculation formula that gives a total score for pain intensity between 0–100. The next three items rate pain-related disability in three specific activities, where 0=not at all and 10=impossible to perform the activities, which is also calculated with a formula to yield a total score for disability between 0–100. The last item concerns how many days the person could not do what they would usually do due to pain during the past month, with a total score between 0–31. Based on the total score, persons with chronic pain are classified into one of four hierarchical categories according to pain severity and interference: Grade I: low disability – low pain intensity; Grade II: low disability – high pain intensity; Grade III: high disability – moderately limiting pain; Grade IV: high disability – severely limiting pain. (130) The CPGQ is a reliable and valid measurement that has been used in a population-based study of adults aged 18–75 years (130, 131). Cronbach's alpha for the CPGQ in was .85 in study I and .71 in study III.

Pain severity and pain-related affective distress

Pain severity and pain-related affective distress were assessed using two dimensions from the Multidimensional Pain Inventory, brief Swedish version (MPI-S) (132), which consists of eight items divided into four dimensions: pain severity, interference, life control and affective distress. The response scale is 0 to 6. Zero corresponds to “no” or “not at all”, and 6 corresponds to “yes” or “very much”. Higher scores indicate higher pain severity/affective distress. The brief version has shown acceptable validity and reliability in older people with pain (132).

Pain-related beliefs

The following questionnaires were used to measure pain-related beliefs:

- The Catastrophizing Subscale (CAT) from the Coping Strategies Questionnaire (CSQ)
- two independent items from the CSQ: *Control over pain* and *Ability to decrease pain*
- The Tampa Scale of Kinesiophobia (TSK))

The CAT consists of six items that assess catastrophic cognitions, where persons indicate how often they have experienced such thoughts (133). The response scale is 0 to 6, where zero is defined as “never think that way” and 6 is defined as “always think that way”. The total score for the CAT can vary between 0 and 36 points. High scores indicate more catastrophising thoughts. Cronbach's alpha for the current sample was .92 in study I and .91 in study III.

For the two independent items from the CSQ, the response scale ranged from 0 to 6, where 0 corresponds to “little control/ability” and 6 corresponds to “very high control/ability”. Low scores indicate low control over pain and low ability to decrease pain. The Swedish version of the CSQ has shown fair to good internal consistency (133).

The TSK (134), Swedish version (87), was used to assess fear of movement/re-injury. The instrument consists of 17 items with a 4-grade response scale, where 1 is defined as “disagree” and 4 is defined as “agree”. The total score can vary between 17 and 68 points. High scores indicate a high degree of fear of movement. The instrument has shown good reliability and validity (35). Cronbach’s alpha for the TSK in study I was .73.

Pain management

The use of different pain management methods and their effects were assessed using a slightly modified version of the Pain Management Inventory, Swedish version, (PMI) (135, 136). The PMI consists of 17 items, which address different pain management methods. Each method used in the last week is marked in the questionnaire. The perceived effectiveness of each method is measured on a 5-point scale: not helpful, somewhat helpful, generally helpful, very helpful, and extremely helpful. The use of methods and their helpfulness were analysed separately. The PMI has shown acceptable reliability and validity (136). In the Cronbach’s alpha analysis in study I, the item “Participation in support groups” and its helpfulness were excluded because none of the women had used the method in the last week. Cronbach’s alpha for the PMI from the current sample was .82 in study I.

Morale

Morale was assessed with the 17-item Swedish version (77) of the Philadelphia Geriatric Center Morale Scale (PGCMS) (67). The response format is yes/no. The total score varies between 0 and 17 and scores of 13–17 indicate high morale, scores of 10–12 are in the middle range, and scores of 0–9 indicate low morale (137). The Swedish version of PGCMS has shown satisfactory inter-rater reliability ($r=.86$) in a geriatric clinic sample (73). PGCMS is recommended for measuring well-being among older people (138).

Self-efficacy beliefs

Self-efficacy in activities

Self-efficacy beliefs in activities were measured using a Swedish version of the Self-Efficacy Scale (SES) (139). It consists of eight different activities (e.g., walking, carrying heavy shopping bags, sitting in a chair, vacuum-cleaning). Each item has an 8-point response scale, where 1 is “less than two minutes” and 8 is “more than 45 min”. The total score can vary between 8 and 64 points. High scores indicate higher self-efficacy in the specific activities.

The Swedish version has been shown to have good internal consistency and test-retest reliability (140). Cronbach’s alpha for the SES scale from the current sample was .60 in study I.

Self-efficacy for exercise

Self-efficacy for exercise was assessed by the Self-Efficacy for Exercise Scale (141), Swedish version, SEE-SV (142). The overall question in the SEE questionnaire is “How confident are you right now that you could exercise three times per week for 20 minutes if, e.g., the weather bothered you, you felt pain when you exercised, you did not enjoy it?” for nine different items. The responses range from 0 to 10, where 0 corresponds to “not confident” and 10 corresponds to “very confident”. The maximum score is 90, indicating high self-efficacy. SEE-SV has been shown to be reliable, with a Cronbach’s alpha of .92, and has satisfactory validity for older people (143). Cronbach’s alpha for the SEE-SV in the current sample was .89 in study III.

Falls efficacy

Falls efficacy was assessed by the Falls Efficacy Scale International (144), Swedish version, FES-I(S) (145). The FES-I(S) assesses the person’s concern about falling during physical and social activities. FES-I(S) consists of 16 items, and the response format ranges from 1-4: not at all, a little, quite a bit and very much. The maximum score is 64 and indicates high concern about falling. FES-I(S) has shown to have high internal reliability (145). Cronbach’s alpha for the FES-I(S) in the current sample was .91 in study III.

Dependency in ADL

Dependency in ADL was assessed with the ADL staircase (146). This instrument was developed specifically for older people. The ADL staircase summarises an individual’s overall performance based on ten activities in personal ADL (P-ADL), e.g., hygiene and getting dressed/undressed, and in instrumental ADL (I-ADL), e.g., cooking and cleaning. The degree of dependency is graded from zero to ten or as “O” (Other) in a specific hierarchical order. Zero defines independence in all activities. ADL scores of 1-4 correspond to the need for help with I-ADL, and scores of 5-10 correspond to the need for help with I-ADL and P-ADL (146). The reliability and validity of this measurement have been shown to be sufficient for older people (147, 148).

Level of physical activity

The level of physical activity, including housekeeping activities, was estimated for the summer and winter seasons according to a six-point scale. The scale ranged from “hardly any physical activity” (level 1) to “hard exercise several times a week” (level 6) (149). The scale has been shown to be valid for older people (108).

Physical tests

The 30-second chair stand test

To assess functional lower extremity strength the 30-second chair stand test was used in study III (150). The women were instructed to rise from a chair (height 44–46 cm) with their arms folded over their chest as many times as possible in 30 seconds. They were told to stand fully erect and sit down properly each time. The 30-second chair stand test has shown to be reliable, including for test-re-test ($r=.89$), for older community-dwelling people (150).

The 2.4-meter gait test

The time taken to walk 2.4 meters (8 feet) was measured at the women's fastest speeds (151, 152). The women used their walking aids and the footwear they normally use indoors. The distance was marked on the floor with green tape, and the women stood just behind the starting line before the test. A digital stopwatch was started when the woman began to walk and was stopped when the first foot crossed the finishing line. The women were told to walk the distance safely, past the finishing line. The walking test has been shown to be reliable for older people (151).

4.3.5 Study IV

Study IV consisted of focus group interviews with home help service staff who had been involved in study III. Three focus group interviews were conducted with the staff. The first interview was conducted with six participants from one home help services area. The two other interviews were conducted with three participants in each interview. The first author led the interviews, and the second author assisted as a moderator. The interviews were audio recorded and lasted for approximately one hour each. The interview guide consisted of two questions: "How would you describe your role in promoting ability in everyday activities among older women who live at home with chronic pain?" and "Can you describe how you promote ability in everyday activities in this group?".

4.4 DATA ANALYSES

An overview of the data analyses for all studies is presented in Table 1 and is described below here. Further descriptions of these analyses can be found in the articles.

4.4.1 Study I

Data were analysed using SPSS version 19.0. Variables were described by frequencies, means, medians and ranges. The independent-samples t-test was used to analyse age differences between participants and dropouts. Correlations were analysed with Spearman's rank correlation test and point biserial correlation (153). Variables that showed significant ($p<0.05$) correlations with the dependent variables pain-related disability and morale were included in an intercorrelation analysis and standard linear multiple regression analyses. Cronbach's alpha was calculated for the measurements that had never or rarely been used among the older population.

4.4.2 Study II

The interviews were analysed with an inductive content analysis, as described by Elo and Kyngäs (154). When there is not enough former knowledge about the phenomenon in relation to the research aim, the inductive approach is recommended (155), which was the case in the present study.

The following analytical steps were performed:

- A first reading was carried out to gain a holistic sense of the content and to identify essential features.
- The features were marked in the text, open coded and then condensed.
- All codes were then compared based on similarities and differences and sorted into groups.
- The categories, subthemes and theme of the content were first constructed, after which the perceived meaning of the women's ability in everyday activities was constructed.

By moving back and forth between steps, the analysis progressed. This methodology formed the basics of the iterative process. Finally, the whole text was reread to corroborate the findings from the analysis.

4.4.3 Study III

Data were analysed using SPSS version 20.0. Variables were also described based on frequencies, means, standard deviations, medians and ranges, and the independent-samples t-test was used to analyse age differences between participants and those who declined to participate. Differences between groups involved chi-squared tests for categorical data, whereas the Mann-Whitney U test was used for ordinal data. Within-group differences were analysed with the Wilcoxon signed rank test, and as in study I, Cronbach's alpha was analysed for some of the measurements.

4.4.4 Study IV

The data from the focus group interviews were analysed based on thematic content (156, 157) based on the researcher's holistic view (157). A theme answers the question "How?" and is considered to be a thread of an underlying meaning through condensed meaning units at different interpretative levels. This allows the researcher to examine both the manifest and/or the latent levels during the analysis. The themes that are created from the analysis can be described as threads of meaning that recur in domain after domain, which are interpreted to be the subthemes and theme in the present study (156, 157).

The analysis was performed using the following steps:

- The text was read through several times, together with listening to the interviews, to obtain a sense of the whole. Meaning units were highlighted according to the aim. Field notes were made in the text about what the text said.
- The meaning units were condensed into interpreted-meaning units, which are descriptions of the manifest content and, where possible, the latent content.
- The interpreted meaning units were seen as a whole and were then abstracted into subthemes, which then were abstracted into a theme(s).

During the analysis, there was a constant forward and backward movement between the whole text and parts of the text as well as between the steps.

4.5 ETHICAL CONSIDERATIONS

It is of high importance to carefully consider ethical considerations when involving older people in research projects, especially if they are frail or may have cognitive impairments.

All women were recruited based on their age, living condition, residence and need of support from the municipality to manage their everyday lives. Thus, they were contacted without having requested any participation or expressed any previous wish or need. Therefore, the women may have felt that their privacy was intruded upon.

One of the inclusion criteria in studies I-III was to have sufficient cognitive capacity, i.e., 24 points or more on the MMSE. Those who did not fulfil the inclusion criteria received both oral and written confirmation that their participation in the study was finished due to the low MMSE score. Both oral and written information were provided because this information should enable the participants who were excluded and/or their relatives to get in contact with the researcher if they had any questions. If the woman had any questions about her cognitive status, they were informed to contact their physician or primary care provider. All home help service groups and their heads or chiefs who were in the actual area were also informed about studies I and III, so they knew that these studies were ongoing if they received any questions from the women or their relatives.

The participants were not expected to be exposed to any unnecessary risks or complications through their participation in the different studies. In study III, there was a risk that the participant might experience more pain due to resulting muscle soreness. The interviews in study II might have led to reflections on how the pain affects the woman's everyday life. However, the interviews could also have helped the women to feel validated because someone was listening to their experiences, which is important.

All participants were given written and oral information about the study that they participated in, and in studies I-III, both oral and written consent were collected, which included their consent for the first author to obtain access to their medical charts for studies I and III. All participants were also reassured that their participation was entirely voluntary and that they could withdraw from the study at any time.

All studies were approved by the Regional Ethics Review Board in Uppsala, Sweden (dnr. 2009/343 and 2013/157).

5 RESULTS

5.1 STUDY I

On average, the women were 81 years old and had four different diagnoses and nine different prescribed medications each. They took no prescribed pain medication but took a median of one non-prescribed pain medication. The women had lived with their pain for approximately 21.5 years and had on average pain at six different body sites. The most common locations for pain were in the lower back, arms, shoulders, hips and knees. The women were affected by pain-related problems, such as walking and mobility problems, and one-third of the women reported impaired sleep quality. The most common and helpful pain management method was to use distractive activities and non-prescribed pain medications.

On average, they received help with six different activities from home help services. The most common restrictions in ADL activities were cleaning, shopping, transportation and bathing. The results showed that 63% of the women were able to go outdoors by themselves. The women reported that they were not as physically active as they wished to be, and most of the social activities that the women participated in took place in the women's own homes.

The women reported low scores of pain severity and affective distress (MPI-S), catastrophising thoughts (CAT subscale), and self-efficacy (SES); high scores of fear of movement (TSK); and low levels of morale (PGCMS). Regarding pain-related disability (CPGQ), 57% of the women scored Grade I (low disability - low pain intensity), 28% scored Grade II (low disability – high pain intensity) and 15% scored Grade III (high disability – moderately limiting pain). None of the women scored Grade IV (high disability – severely limiting pain). The descriptive statistics for affective distress, pain-related beliefs, number of pain management methods, and morale are reported in Table 4.

The multiple regression analyses showed that the independent variables ADL, the number of years with pain, pain severity, the ability to decrease pain, pain catastrophising thoughts and the number of pain management methods used explained 35% of the variation in pain-related disability (CPGQ) ($\text{Adj } R^2=0.35$, $F=4.85$, $p<0.001$). In this regression model, the only independent variable that was shown to be significantly related to pain-related disability was pain catastrophising thoughts, which was positively related to pain-related disability. Furthermore, the independent variables physical activity, affective distress and pain catastrophising thoughts explained 56 % of the variation in morale ($\text{Adj } R^2=0.56$, $F=26.25$, $p<0.001$). In this regression model, affective distress and pain catastrophising thoughts were significantly negatively associated with morale. Thus, having pain catastrophising thoughts was the only variable that was independently associated with both pain-related disability and morale. Table 5 presents the B, Beta, and p-values for the different independent variables.

Table 4. Descriptive data (mean, range) for morale, pain-related beliefs, self-efficacy in activities, pain severity, affective distress and number of pain management methods (n=60)

Variable	Mean	Range
Pain severity (MPI-S, 0-6)*	2.8	0.5-6.0
Affective distress (MPI-S, 0-6)*	1.8	0-6
Control over pain (CSQ, 0-6)**	2.1	0-6
Ability to decrease pain (CSQ, 0-6)**	2.1	0-6
Catastrophising thoughts (CAT, 0-36)*	7.3	0-36
Fear of movement (TSK, 17-68)*	38.9	0-59
Self-efficacy Scale (SES, 8-64)**	28	19-43
Number of pain management methods used (PMI, 0-17)**	4.7	0-11
Morale, as medians, (PGCMS, 0-17)**	10	0-15

*=low scores indicate a low degree of pain severity, affective distress, pain catastrophising thoughts, or fear of movement

**=high scores indicate a high perception of being able to take control over pain and ability to decrease pain, high self-efficacy in relation to different everyday activities, high use of different pain management methods and high morale

Table 5. Results of the multiple regression analyses in relation to pain-related disability and morale (n=60)

Model	Pain-related disability (CPGQ)			Morale (PGCMS)		
	B	Beta	P-value	B	Beta	P-value
Dependency in ADL (ADL staircase)	.06	.15	ns			
Physical activity				-.87	-.11	ns
Number of years with pain	.00	.16	ns			
Pain Severity (MPI-S)	.09	.19	ns			
Affective distress (MPI-S)				-.92	-.42	.001
Ability to decrease pain (CSQ)	-.85	-.20	ns			
Catastrophising thoughts (CAT)	.24	.28	.04	-.19	-.45	.001
Number of pain management methods used (PMI)	.06	.22	ns			

5.2 STUDY II

Two general themes emerged in relation to the analysis. The general theme of the women's abilities to perform activities in everyday life and what promoted their abilities was explored as *A daily rhythm of activities in a supportive environment*. The general theme from the women's description of their perceived meaning of their changed abilities was explored as *To accept, adapt and be dependent, with a feeling of independence and safeness*.

In the results, all activities that the women performed also promoted their ability to perform their everyday activities in different ways, which helped them to keep track of weeks and days. The theme about the importance of a daily rhythm consisted of two subthemes: *Everyday doing and promoting activities* and *Activities in a supportive environment*.

Everyday doing and promoting activities included all types of activities, such as managing one's own hygiene, reading a book, solving crossword puzzles, watching TV, exercising and socialising with family and friends. Performing these activities promoted the women's physical and mental health.

The activities in a supportive environment included support from relatives, the home help service staff, health care and voluntary support. The home help service staff supported the women in their personal individual care, and relatives supported the women mainly in housekeeping activities. The support from relatives included family, friends and neighbours.

Regarding the support from the health care services, the women experienced support from the health care system through different types of aid. However, some wished to have access to more home-based care or rehabilitation. The support from voluntary organisations consisted of transportation and company.

The general theme *To accept, adapt and be dependent with a feeling of independence and safeness* consisted of the categories *Acceptance, Adaptation, Dependence, Independence* and *Safeness*. *Acceptance* and *Adaptation* referred to the women's experiences about how their lives had changed, and many different factors, not just the chronic pain, limited their abilities to perform everyday activities (e.g., mobility problems, physical limitations, lack of energy and fatigue). These categories also dealt with the need to accept assistance/aid and to accept and adapt to one's feelings of loneliness. Despite their changed life situations, the women experienced feelings of being content. The importance of being able to live in one's own home as long as possible was clearly described.

Dependency was associated with being dependent on others and/or on aid/assistance to manage their everyday lives. It also involved the experience of not being able to do things when one wanted to do them. Although the women depended on support to manage their everyday lives, they highlighted the importance of being *Independent*, which referred to taking their own initiatives and doing their own activities. Environmental conditions promoted their independence in different ways, e.g., having an elevator in the house or living near a shopping mall and library. The last category, *Safeness*, referred to how alarm

equipment made the woman feel safer at home, how continuity among the home help service staff could both promote and inhibit the ability to pursue everyday activities and how economic resources affected their everyday lives.

5.3 STUDY III

Of the 23 women who agreed to participate, 16 women (69%), including nine in the experimental group and seven in the comparison group, completed the intervention. No significant differences were found at baseline between the experimental and comparison group in terms of demographic data or in the included assessments. Furthermore, no significant differences were found between dropouts and participants regarding age, MMSE scores, number of hours of home help service per week, number of years with pain, number of diseases, pain intensity, disability scores, disability grades or morale. The demographic characteristics of the sample are presented in Table 6.

Table 6: Demographic characteristics for the participants

Baseline characteristics	Experimental Group (n=12)	Comparison Group (^an=11, ^bn=10)	P-value
Age, mean (SD)	84.5 (6.7)	83.8 (4.9) ^a	.57
MMSE, mean (SD)	27.7 (1.3)	27 (1.3) ^a	.22
Years with pain, mean (SD)	28.8 (21.8)	26 (22.1) ^b	.21
Help from relatives, % yes (no)	75 (25)	72 (18) ^b	.78
Home help services, number of visits per week, mean (SD)	17.3 (6.7)	15.6 (9.5) ^b	.56
Get outdoors by themselves, % yes (no)	58 (42)	27 (63) ^b	.18
Number of diseases, mean (SD)	3.6 (1.2)	3.1 (1.8) ^a	.06
Number of medications, mean (SD)	8.3 (4.0)	5.2 (1.7) ^a	.65
Number of prescribed pain medications, mean (SD)	0.57 (0.78)	0.29 (0.49) ^a	.96
Number of non-prescribed pain medications, mean (SD)	0.99 (0.35)	1 (0) ^a	.56

The intervention was found to be feasible in the home environment. Some issues were found regarding the study procedure. Issues regarding the intervention included an overall perception that it was difficult for the participants to describe their goal behaviour, even if it was easier for some of the women, problems with individual adaptation regarding balance training and enabling outdoor training. Additionally, the reminders from the home help service staff did not work out as planned. Issues that were recognised in both groups were filling out the activity diaries, and the SEE-SV was difficult for the participants to answer.

The results showed that, on average, all women reached the goal of being physically active on at least five of seven days, but only the women in the experimental group reached the goal of being physically active for at least 30 minutes. Regarding being physically active, the field notes indicated that some of the women expressed that they had become more aware of the importance of being physically active. The recorded field notes also showed that the majority of the women, regardless what group they belonged to, had a positive impression of the intervention.

No significant differences were found for the primary outcomes pain-related disability or morale between the groups or within the groups at any of the follow-ups. A significant difference between the experimental and the comparison group for pain catastrophising thoughts was found ($p < .001$) between follow-ups 1 and 2, which showed a higher degree of pain catastrophising thoughts in the experimental group. No other significant differences were found between the groups. Regarding differences within the groups, in the experimental group, there were significant increases in the degree of self-efficacy for exercise, ($p < .05$) and the level of physical activity ($p < .05$) as well as a decrease in gait speed ($p < .05$) at follow-up 1 compared with baseline. Additionally, significantly higher concerns for falling ($p < .05$) at follow-up 2 compared with follow-up 1 were found in the experimental group. In the comparison group, there was a significant increase in affective distress, measured using the MPI-S ($p < .05$), at follow-up 1 compared with baseline. More specific details about the results are shown in Table 7.

Table 7. Descriptive results presented as mean (SD) and significant differences for the effects of the intervention, within and between groups

	Experimental Group			Comparison Group			Between Groups	
	Baseline (n=12)	Follow-up 1 (n=10) with significances for baseline – follow-up 1	Follow-up 2 (n=9) with significances for follow-up 1 – follow-up 2	Baseline (n=11)	Follow-up 1 (n=7) with significances for baseline – follow-up 1	Follow-up 2 (n=7) with significances for follow-up 1 – follow-up 2	Significances for baseline – follow-up 1	Significances for follow-up 1 – follow-up 2
Pain intensity, CPGQ (0-100)¹	46.1 (30.9)	59.4 (21.7)	64.8 (21.0)	50.6(19.7)	54.3 (24.3)	49.7 (24.9)	ns	ns
Disability score, CPGQ (0-100)¹	30.3 (20.2)	32.9 (29.2)	43.4 (36.7)	15.9 (18.5)	32.7 (29.1)	19.9 (25.1)	ns	ns
Morale, PGCMS (0-17)²	9.0 (3.6)	8.3 (2.3)	7.9 (2.2)	10.1 (3.9)	10.4 (2.3)	9.0 (3.9)	ns	ns
Affective distress, MPI-S (0-6)¹	2.5 (2.5)	2.1 (1.9)	1.8 (1.4)	0.5 (1)	2.7 (2.3)*	.79 (1.5)	ns	ns
CAT, CSQ (0-36)¹	8.6 (11.1)	8.3 (11.3)	13.6 (12.7)	5.5 (5.5)	11.7 (14.3)	6.7 (7.6)	ns	**
Control over pain, CSQ (0-6)¹	2.2 (1.6)	2.7 (1.6)	2.6 (1.5)	1.6 (2.1)	2.6 (1.3)	1.4 (2.3)	ns	ns
Ability to decrease pain, CSQ (0-6)²	1.4 (1.8)	1.3 (1.6)	2.1 (1.7)	0.8 (1.4)	1.0 (1.7)	1.6 (2.1)	ns	ns
FES-I(S) (0-68)¹	41.1 (11.2)	37.6 (12.2)	43.4 (11.6)*	38.5 (9.0)	40.4 (9.7)	42.9 (10.2)	ns	ns
SEE-SV (0-90)²	46 (28.4)	71.2 (18.9)*	58.7 (37.0)	25.6 (26.4)	32.0 (20.3)	36.0 (32.3)	ns	ns
Physical activity scale (1-6)²	2.4 (.51)	2.7 (.48)*	2.6 (.53)	2.4 (.52)	2.6 (.54)	2.6 (.54)	ns	ns
30-second chair stand test,	3.5 (3.8)	3.1 (3.5)	2.2 (3.5)	1.6 (2.6)	0 (0)	0 (0)	ns	ns
2.4-m gait test, seconds	12.2 (20.1)	20.2 (37.8)*	17.9 (30.4)	7.5 (2.9)	9.8 (5.2)	6.8 (9.7)	ns	ns

*p <.05; **p <.001. ¹low scores indicate a low degree of pain intensity/severity, pain-related disability, affective distress, pain catastrophising thoughts and concerns to fall; ²high scores indicate a high perception of being able to take control over pain and ability to decrease pain, high self-efficacy in relation to exercise, high level of physical activity and high morale

5.4 STUDY IV

The results highlighted four subthemes and one theme. The subthemes consisted of the following: *Being the driving force and being involved in the front line*; *Managing complex situations*; *Creating conditions for activity* and *Managing conflicting demands and desires*. The theme that emerged was ***Struggling to improve the care recipients' opportunities for independency but being inhibited by complex environmental factors***.

The results showed that the staff considered their role in promoting ability in everyday activities to be an important part of their everyday work. Nonetheless, promoting abilities in everyday activities was perceived to be more or less easy due to, for example, the care recipients' health status, management of the care recipients' and/or their relatives' will and desires. The staff also perceived that the system ruled their everyday work. The staff expressed how they perceived their role as being associated with a large and sole responsibility due to the complex situations that they faced in their everyday work. An ethical dilemma that emerged from the results was that the staff might consciously hinder the care recipients' opportunity to maintain independence or become more independent in the present context. Reasons for perceiving that they were hindering the care recipients' abilities were related to, e.g., forgetting to ask the care recipients if they wanted to do or could do the activity by themselves and wanting to be nice and helpful; in the end, a staff member did not want to be seen as a "mother". Additionally, the staff perceived chronic pain as a common problem among their care recipients. However, the staff did not perceive any particular difference in promoting everyday activities among the target group of older women with chronic musculoskeletal pain compared with other care recipients, even if the staff stated that the pain could hinder everyday activities.

The staff described how they perceived both maintenance and improvement of independence and improvement of the quality of life of the care recipients by promoting the recipients' abilities in everyday activities. They also narrated how their roles, in the context of the present study, required that they facilitated the care recipient's self-esteem and self-confidence, strengthen her desire to take command of her own life and strengthen her self-efficacy in relation to performing different types of everyday activities. The staff always did their best to have the care recipient's needs in focus and to try to involve the person in the everyday activities as much as possible to create opportunities for activity. This focus required that the staff to be adaptive, flexible and responsive to the care recipient. The staff had to be proactive, be able to create goals such as those for physical activities, be able to see how environmental factors such as changes in the apartment could promote the care recipient's ability to perform everyday activities, and have a rehabilitative approach; these actions helped the staff to optimise their work. To take time that did not really exist was another action that the staff employed. The time factor was also associated with stress. Finally, the results revealed how the staff felt that their competence and knowledge was not being optimally utilised in the context of promoting the ability to perform everyday activities.

6 DISCUSSION

To my knowledge, this is the first thesis that has used a behavioural medicine approach in physiotherapy to study how older women with chronic musculoskeletal pain, living alone and dependent on formal care, perceive their everyday lives and to explore how their ability to perform everyday activities and morale could be promoted. The theoretical framework for the thesis has fruitfully helped to identify different factors that may impact the ability to perform everyday activities and improve morale for the target group of older women. The framework has also developed and evaluated a first step towards an evidence-based intervention to promote ability in everyday activities in the target group of older women.

Overall, the results showed that the women's everyday lives were affected by pain-related disability and the same common pain-related problems as presented in the literature. The women reported a low degree of affective distress, pain catastrophising thoughts and self-efficacy in relation to different everyday activities but a higher degree of fear of movement and low levels of morale. The women also reported that they were not as physically active as they wished to be. The results revealed that the women had a strong desire and wish to "age in place". Having a daily rhythm in a supportive environment promoted their abilities to perform everyday activities. The home help service staff members were key persons in the context of promoting the women's abilities in everyday activities. Nevertheless, both the women and staff described how the staff could hinder the women in their abilities to perform everyday activities. The feasibility study indicates that an intervention based on a behavioural medicine approach in physiotherapy is feasible to conduct; the results are encouraging, but further research is needed in a larger sample cohort.

6.1 AN AGEING POPULATION AT HOME

Previous research has shown that being an older woman, having chronic musculoskeletal pain, living alone and being dependent on formal care are all factors that are associated with, poorer health, a higher degree of functional decline, a higher degree of pain, pain-related problems, lower levels of physical activity, a higher risk of social isolation, depressive symptoms, and finally, a poorer quality of life, to varying degrees (13, 14, 16, 17, 53, 55, 158). The results from the present thesis are overall consistent with these associations. Therefore, this specific group of older women may be considered a vulnerable group among the older population and may also require special attention from society and health care professionals.

Older people should be able to live at home as long as possible under good circumstances and to live an independent life of good quality (25, 37). They should also have the possibility of "ageing in place" (32). The results from study II showed how important it was for the women to live at home as long as possible, despite their dependency on others, to manage their everyday lives. However, the results indicate that there seems to be a potential to optimise their ability to "age in place". A crucial factor in this context is to maintain and improve the women's capabilities to perform everyday activities (22, 41), which in turns promotes their

independence and improves both their morale and their level of physical activity, which are further discussed below.

A key factor that emerged to promote the ability to perform everyday activities was to perform them in a daily rhythm in a supportive environment. Using a daily rhythm helps to re-establish everyday life for older people who are living alone when life changes due to loss of health (42), and these findings are also consistent with the results from the present thesis. When encouraging one to turn the activities into a daily rhythm in a supporting environment, it is important to establish a rhythm based on the individual's needs and wishes. The behavioural medicine perspective that was used in this thesis strongly advocates a person-centred perspective (7). However, further research is needed to explore in detail how a daily rhythm can maintain and improve both independence and morale among the target group of older women.

Another key feature in optimising the women's ability to "ageing in place" was the home help service staff. Both the women and staff described how the staff helped but also hindered the women as the women tried to maintain and improve their ability in everyday activities. These experiences have also been reported in recently published studies in which older people described how home help service staff both helped and hindered their independency and participation in everyday life and the staff reported the same experiences (34, 159, 160). One of the greatest hindrances for the staff was lack of time, insufficient teamwork among the staff as well as well insufficient team work among the whole team and insufficient support from other team members, such as nurses, physiotherapists, occupational therapists and care administrators. The results from the present thesis are in agreement with recently published research, which has identified the same hindrance for the home help service staff in Sweden as well as in other countries, to promote independence and participation among older individuals dependent on formal care (35, 159, 160). A published review about teams and teamwork in the field of the care of older people has shown that teamwork is both necessary and effective to meet the older people's needs for care and rehabilitation (161). Therefore, a well-functioning team is important when discussing how independence and well-being can be improved for the target group of women.

The women's opportunities to be independent or participate in the community were also sometimes hindered by environmental factors in the municipality, such as accessibility to elevators in the apartment building or by distance from a shopping mall or library. The women also expressed the need for more support to enhance their opportunities to get outdoors and enable them to go to, for example, a shopping mall whenever they want. This mobility is important because these women are at high risk of being socially isolated or are already socially isolated (47). Finally, the women expressed that they wished to have access to more home-based care and rehabilitation, which would hopefully help them "age in place" and participate in everyday life in a better way.

6.2 OLDER PEOPLE'S PAIN-RELATED BELIEFS AND DISABILITY

With respect to living alone and its association with higher degrees of pain (17), the results indicate that the women reported the same prevalence of pain and pain severity compared with similar studies that have examined older people living at home with support from the community (61, 158). The women reported the same common pain-related problems, such as mobility and walking problems, fatigue/lack of energy and sleep disturbance, that previous studies have reported (47). The results also showed that the women reported similar degrees of pain-related disability when comparing the results with previous research in community-dwelling older people (162). Regarding the results for pain-related disability, only two women, both in study III, scored Grade IV (high disability – severely limiting pain) on the CPGQ. One assumption that might explain this result is that the women's abilities to perform everyday activities and participate in everyday life are limited by more than just pain. This assumption may also explain why there seems to be no difference in the prevalence of pain-related disability among older people who are dependent on help to manage their everyday lives, regardless of whether they are living with or without chronic pain (61).

Research has shown that there seems to be no apparent differences in the prevalence of disability among older people living with chronic musculoskeletal pain compared with those without pain. Leveille et al. (60) found no differences in the prevalence of disability in their population-based study on community-dwelling older women who lived in the USA with some type of disability, e.g., difficulties in ADL performance or mobility problems. Similar results were shown in a Swedish study among older people who were dependent on help to manage their everyday lives (61). Nonetheless, chronic pain is associated with pain-related disability among older people (49, 52, 60), particularly among older women living with widespread musculoskeletal pain (51). Thus, the target group of older women is a high-risk group for developing pain-related disability and mobility problems, and the results showed that they had pain at an average of six different sites in their bodies. Therefore, health care professionals must reduce pain-related problems, particularly for older women.

Factors such as fear avoidance and pain catastrophising thoughts have a negative impact on pain-related disability and quality of life, at least among working-age people with different chronic musculoskeletal pain conditions, and especially among women (89, 163-165). The results from the present thesis indicate that the women had a high degree of fear of movement, low scores for pain catastrophising thoughts and low scores for affective distress. Despite the low scores for pain catastrophising thoughts, the multiple linear regression analysis indicated that pain catastrophising thoughts seem to be the only factor that was independently associated with both pain-related disability and morale, whereas affective distress was shown to be associated with morale alone. These results indicate that there does not seem to be any difference from what is shown for working-aged people, as mentioned above. Even if the results did not show any significant correlations between fear of movement and morale or pain-related disability, other studies have reported these variables as mediators

of pain-related disability (166) and, therefore, are also factors that require attention. With these results in mind, a suggestion to reduce pain-related disability and improve morale in the target group of women would be to focus on pain catastrophising thoughts when developing interventions. This focus, as well as other pain-related beliefs, e.g., affective distress, is also emphasised in the behavioural medicine approach in physiotherapy (7).

6.3 MORALE

The results indicate that the women had lower morale compared with the results of previous research including community-dwelling older people (69, 76). Knowing that morale can be affected by both personal and environmental factors, may the results for morale from the present thesis not be so surprising. (67). Even if the women are living in ordinary housing, which is positively related to morale (69), and they seem to be satisfied and accept what cannot be changed, they may still be struggling with different demands and challenges. Additionally, older people who are dependent on formal care and older people living with chronic pain, especially older women, have a lower quality of life or morale (40, 73).

It is important to improve the level of morale to reduce the negative consequences with which low morale is associated. To improve the level of morale among the women, it is necessary to, e.g., meet their rehabilitation needs, strengthen their ability to perform everyday activities (76) and their functional capacity and cognitive function (70, 71) and decrease the risk of social isolation (70). Regarding improvement of cognitive function, the women described how their performance of different everyday activities promoted both their physical and mental health, which in turn can improve their morale. In summary, higher morale may promote both independence and the possibility of “ageing in place” in a better way for the women, but further research is needed.

Another action that can be used to increase morale is to decrease depression and depressive symptoms, which are strongly associated with morale (18,69,75). Even if the prevalence of depression was not measured in the present thesis, living with chronic pain as an older adult is associated with both depression and depressive symptoms (47). Therefore, we suggest that health care professionals should always screen for depression when evaluating older people with chronic pain.

6.4 BEHAVIOURAL MEDICINE IN PHYSIOTHERAPY INTERVENTIONS

Overall, the study results were encouraging, even if some issues were identified. The results imply that this type of intervention among the target group of women requires more support from the physiotherapist and the home help service staff. Previous research has also shown that it is more complicated for older people to initiate, perform and maintain behavioural changes due to disabilities and diseases, cognitive decline and lack of available support (96, 98), among other factors. For example, having the available support of a physiotherapist may have improved the effects of the balance exercise in relation to the goal behaviour because the women expressed that they did not want to do more advanced training due to a fear of falling. Another assumption is that if the women received support from the staff to fill in the

activity diaries, this support may have impacted the women's opportunity to make behavioural changes in a higher degree.

The results indicate that the level of physical activity had been promoted, which is of particularly clinical interest due to the knowledge that older women with chronic pain who are living alone are less physically active than older people in general and those without pain (14, 106). To be physically active is essential for and central to older people with regard to maintaining and lengthening an independent life, improving their physical and mental health, increasing their participation and reducing falls (105, 167). Additionally, morale may be improved by physical exercise, at least among older people living in residential homes (79).

A recently published study discusses how the benefits of being physically active can be optimised for older people using exercises that focus on functional daily tasks/activities (168). The authors' descriptions of these intervention strategies are in agreement with the behavioural medicine intervention in physiotherapy in the present thesis. Another type of exercise that may optimise the effects of this type of intervention is the use of a HIFE program, which has been shown to be beneficial for older individuals who are dependent on help in everyday activities and for older persons living in residential care facilities (169, 170). The results from study I also show that many women wished to be more physically active, and this wish and their needs should be considered by health care professionals.

Another key factor is self-efficacy, and it is important to encourage and enhance the women's self-efficacy to reduce functional decline, pain-related beliefs and disability (94, 171). To have high self-efficacy in relation to performing everyday activities might also have had an impact on the morale of the target group. Therefore, this result is of great interest because it implies that self-efficacy may be a contributing factor. The results imply that the women could manage their everyday lives in a better way after participating in the study. The results from study IV also describe how the home help service staff perceive how they encourage the women's self-efficacy in different activities with the goal of improving their independence and quality of life.

In summary, further research is needed to explore which individuals will benefit the most from this type of intervention. More research is also needed to explore whether HIFE can improve the goal behaviour and whether it can affect an individual's morale.

6.5 METHODOLOGICAL CONSIDERATIONS

The use of both quantitative and qualitative research methods was needed to capture the multidimensional view for the overall and specific aims of this study. This strategy was both fruitful and invaluable for the thesis as a whole as well as for the individual studies.

Procedure and data collection

To improve the participation rate, all studies were conducted in the women's homes, and all questionnaires were administered through interviews. The choice of the data collection method might have threatened the internal validity because the questionnaires needed to be filled in without any interference. However, the choice of the data collection method may have strengthened the external validity of the results because there were few missing data in studies I and III. Regarding the data collection in study I, informing the home help service staff before the start of study I was very successful. This strategy allowed the staff to act as gatekeepers for the care recipient and/or his or her relatives in terms of confirming that the study was ongoing.

The low sample size and participation rate in studies I and III might have threatened the external validity of these studies (172). The small sample size might also have been a risk for type 2 error in studies I and III (153). An aspect that might have strengthened the external validity is that study I was a population-based study, because all women who lived in the area were invited to participate. Although the study sample was small, the results may still be generalisable to women with chronic musculoskeletal pain who live in similar settings.

An issue in study III was that the women in the experimental group were expected to perform the exercises on their own. This expectation was a problem, especially when they needed to perform balance training, which should be performed at the limit of the person's capacity in order to challenge postural stability while still being performed safely to achieve maximum effect. No participant should have been injured during their participation in the study. Thus, we did not expect the women to expose themselves to any risks, and we can confirm that no injuries related to the intervention were registered.

The questionnaires

Some of the questionnaires in studies I and III had not been widely used previously in an older population and therefore, the internal validity and reliability of the questionnaires may be a source of bias. However, the Cronbach's alpha scores showed that the internal consistency of these measurements was satisfactory. Regarding the questionnaires, an overall perception is that it was more difficult for the women to understand and answer questionnaires that were based on numeric rating scales without any explanations, compared with measurements that were based on verbal rating scales.

The questionnaires that were perceived to be particularly difficult to understand were the TSK, SEE-SV and FES-I (S). The TSK was difficult to answer due to the wording of the questions, and most of the women preferred to score their answers as 1 (strongly disagree) or 4 (strongly agree), without using the scores in between. The SEE-SV was perceived to be

difficult for the women to answer because it did not define what was meant by “exercise”. The SES, SEE-SV and FES-I(S) were sometimes found to be difficult for the women to answer because they were based on hypothetical questions (e.g., “even if you cannot clean the floor, how concerned would you be about falling if you should do it?”). In summary, further research is needed to explore the reliability and validity of these questionnaires, e.g., the CPGQ, TSK and CAT subscale, and to develop questionnaires that better fit the older population in relation to the context of this thesis.

Trustworthiness and transferability of the results

The transferability of the behavioural medicine in physiotherapy interventions into clinical settings may be a bit problematic because it requires both education and supervision for the physiotherapists, at least in the beginning (116). This knowledge and competence is promising when meeting older people with chronic musculoskeletal pain when the goal is to promote their ability to perform everyday activities and their well-being. Therefore, we would like to state that this knowledge and competence are growing among physiotherapists, at least in Sweden.

To assure and strengthen the trustworthiness of the qualitative studies, different actions were taken. The use of strategic sample selection in both studies increased the possibility of shedding light on the research question (173). The content in the interviews and focus group interview was rich and should therefore contribute to the credibility of the studies. To reduce the risk of subjectivity in the analyses, the analyses were performed separately by the first and last author in respective study. The analyses were also discussed several times and validated by the co-authors in an open dialogue until a consensus was reached. In study IV, the analysis was also discussed in the research group. To facilitate the transferability of the results, a clear description of the context, how the participants were selected, and the characteristics of the participants have been provided. To make the research process visible to the reader, examples of the analysis process, from meaning units to subthemes and theme(s), and quotations from study participants have been provided.

There is a need to be aware of reflexivity when undertaking qualitative research (174), but the researcher should be aware of this concept regardless of the research method. The pre-understanding that the authors had might have affected both data collection and analysis. However, these experiences might also have helped to understand the context in a better way. Additionally, we are aware that a single person collected all of the data and performed the main work in relation to the data analysis in all four studies. Yet, the use of a single person might have improved the validity of the data collection.

7 CONCLUSIONS

The present thesis has filled in some of the research gaps related to how the target group of older women perceive living with chronic musculoskeletal pain and how their ability to perform everyday activities can be promoted. In comparison with previous studies, the results showed that the target group of older women reported a similar degree of pain-related disability and pain-related beliefs but a lower morale than has been shown previously. Additionally, although the women scored low degree of pain catastrophising thoughts, this was the only variable that was independently associated with both pain-related disability and morale. The results also showed that performing everyday activities, managing one's own hygiene, reading books, being physically active and socialising with family and friends were activities that promoted the women's ability to perform everyday activities. Performing the everyday activities in a supportive environment was regarded as important. The home help service staff were described by the women to be important in promoting their ability to perform everyday activities, but the staff were also described as hindering the women in their everyday activities. The latter was also perceived by the staff in the last study. The results indicate that the role that the staff play in this context could be performed in a more efficient manner. The feasibility study implied that the behavioural medicine in physiotherapy intervention could facilitate both the level of physical activity and self-efficacy in relation to exercise and the management of everyday life in a better way for the target group. However, the study methodology and procedures require further development and should be tested using larger cohorts studies. In summary, the results from the present thesis indicate that the target group of older women is a group that may need special attention by society and health care professionals. The results from the present thesis also suggest that the target group of older women can "age in place" in a better way with high morale.

8 CLINICAL IMPLICATIONS

The results from this thesis suggest how a behavioural medicine approach in physiotherapy can be used for the target group of women, from the identification of activity limitations to the development of interventions. The approach may also be useful in other contexts and settings that involve older individuals in different ways.

The results describe how a daily rhythm seems to promote the performance of everyday activities. This insight can most likely be used in other settings and contexts.

Due to the impact that pain catastrophising thoughts seem to have on both pain-related disability and morale, pain catastrophising thoughts are of particular interest to screen for when assessing the target group of older women and likely also older people in general with chronic pain. Even if the results did not show any significant correlations between fear of movement and morale or pain-related disability, require these factors also attention due to that earlier research has found them to be mediators of pain-related disability.

The results from the present thesis indicate that the target group of women score their morale as low when compared with the results of previous studies. Due to the negative consequences of low morale, it is of high importance to improve the level of morale. This improvement can be made in various ways, such as meeting rehabilitation needs, strengthening ADL ability, functional capacity and cognitive function and decreasing the risk of social isolation. Low morale is also strongly associated with depression and depressive symptoms. Therefore, screening for depression and depressive symptoms is recommended when assessing older people with low morale.

Self-efficacy is a crucial factor that should be used by health care professionals when discussing the improvement of a person's ability to perform everyday activities and when in the context of promoting behavioural changes.

Finally, the home help service staff are a key resource for promoting the ability to perform everyday activities and improving the quality of life among older people who live in ordinary housing and are dependent on formal care, and this resource can be utilised in a more efficient and beneficial manner.

9 FUTUTRE OUTLOOKS

Further research is needed or is of interest in the following areas:

- Validation and reliability tests for the questionnaires and measurements used in the context of this thesis,
- Development of questionnaires for measuring self-efficacy in relation to everyday activities that are common for older people and the development of more suitable measurements for pain-related disability among older people, among other factors.
- A comparison of older men with chronic musculoskeletal pain who are living alone with support from the community to older women in the same setting to investigate differences regarding how they manage their chronic pain, rate their morale, or promote their ability to perform everyday activities.
- Further investigations of the low morale among the target group of women and the relation between morale and functional decline.
- Refinement of the feasibility study and an evaluation of the interventions in a larger study sample with the goal of reducing pain-related disability, reducing pain-related beliefs, enhancing self-efficacy in everyday activities and improving morale in the target group of older women.
- Investigation of which population benefits the most from a behavioural medicine approach in physiotherapy intervention and the identification of populations for which this approach might not work.
- Evaluation of whether the effects of behavioural medicine in physiotherapy interventions can be optimised using HIFE programs as well as development of activity diaries adapted for older people.
- Development and evaluation of how health care professionals can use the concept of self-efficacy to enhance and improve independence and quality of life among older people who are receiving formal care from the commun.

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