Finding ways forward with pain as a fellow traveler

Older women's experience of living with osteoporotic vertebral compression fractures and back pain

Hilda Svensson

Center for Person-Centered Care (GPCC)

Institute of Health and Care Sciences

Sahlgrenska Academy at
the University of Gothenburg, Sweden

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hilda.svensson@gu.se

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ABSTRACT

In a globally aging population, the number of older people living with physical disabilities due to persisting conditions will increase. Within the population of older women, two common conditions leading to long-term back pain are degenerative disc disorder and osteoporotic vertebral compression fractures, with subsequent poorer health-related quality of life and reduced well-being. The aim of this thesis was to achieve a comprehensive understanding of older women's experience of living with osteoporotic vertebral compression fractures and back pain.

Study I had a descriptive cross-sectional design based on an epidemiological study (Gothenburg H70 Birth Cohort Studies) comprising both self-reported outcomes in the form of questionnaires and objective physical measurements, in older women with long-term back pain. Study II also had a cross-sectional design and comprised a similar source of data, but from another epidemiological study (SUPERB), in older women with clinical vertebral compression fractures aiming to determine health-related quality of life over time. Study III was a systematic literature review aiming to explore level of current knowledge of interventions within the population of older women with osteoporosis and vertebral compression fracture, whereas Study IV had a qualitative design, aiming to illuminate the lived experience of women with osteoporosis and vertebral compression fracture.

The results revealed a low health-related quality of life and reduced physical ability in women with long-term back pain, however with discrepancies, in that the women reported an equal level of sense of coherence and self-reported physical ability as the women without back pain. Women with clinical vertebral compression fracture, however, showed a similar level of physical ability and mental health-related quality of life as women without fractures but reported a reduced physical health-related quality of life up to 18.9 years post fracture. The interventions that have been implemented within the population of older women with osteoporosis and vertebral compression fractures, mainly included physical activity and have revealed probable effects on primarily physical mobility and health-related quality of life. However, since this population has a substantial symptom burden, e.g. back pain and reduced physical ability, there was a risk of selection bias in that the women with the most illness experience were excluded. Ten women describing their lived experience of living with osteoporosis and vertebral compression fracture painted a dark picture of turmoil, insecurity and chaos, creating restraints and missed opportunities through fear and concerns about pain experience and living with a deceptive body. Nevertheless, even though the women in this thesis reported reduced health-related quality of life and physical ability, together with fear and concerns due to vertebral compression fracture and long-term back pain, there was a sense of resilience and strong will-power not to give up, but to keep struggling on their own to continue finding ways forward.

Keywords: older women, back pain, vertebral compression fracture, osteoporosis, degenerative disc disorder, health-related quality of life, transition

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SAMMANFATTNING PÅ SVENSKA

Världens befolkning bli allt äldre och inom denna åldrande befolkning finns fler kvinnor än män. Kvinnor drabbas också oftare av benskörhet, framförallt efter klimakteriet bland annat pga. minskat östrogen. Benskörhet är en skelettsjukdom som kännetecknas av låga nivåer av benmineral vilket leder till urkalkning och skörhet av benvävnad. Detta ökar risken för frakturer av höft, kota, underarm och överarm, som i sin tur leder till både illabefinnande och lidande. En av de vanligast förekommande benskörhetsfrakturen är vertebral kompressionsfraktur orsakad av frakturkollaps av en eller flera av ryggkotornas kotkroppar. Den vertebrala kompressionsfrakturen leder ofta till kraftig ryggsmärta med minskad fysisk förmåga och minskat välbefinnande. Avhandlingens huvudsakliga syfte var att söka en övergripande förståelse för äldre kvinnors upplevelse av att leva med benskörhet och vertebrala kompressionsfraktur eller annan ospecifik ryggsmärta.

För att försöka uppnå detta började vi med att studera 70-åriga kvinnor födda 1944, boende i Göteborg med långvariga ryggsmärtor i populationsstudien H70. Kvinnor med långvariga och intensiva ryggsmärtor jämfördes med kvinnor utan ryggsmärta utifrån fysisk funktion, livskvalitet, känsla av sammanhang, dagliga aktiviteter och instrumentella aktiviteter i det dagliga livet. Resultatet visade att kvinnornas rapporterade intakt fysiska förmåga i stort sett i samma utsträckning men de fysiska testerna visade på stora skillnader i fysisk funktion mellan de båda grupperna. Kvinnorna med ryggsmärtor uppgav betydelsefullt sämre hälsorelaterad livskvalitet men med likvärdig känsla av sammanhang som kvinnorna utan ryggsmärta.

Vi gick vidare i en annan populationsstudie Sahlgrenska University hospital prospective evalutation of risk of bone fractures (SUPERB) och studerade en grupp av kvinnor mellan 75-80 år och med diagnostiserade vertebrala kompressionsfrakturer. Syftet var att undersöka kvinnornas hälso-relaterade livskvalitet jämfört med en grupp med kvinnor utan ryggskada samt att studera om det fanns samband mellan hälsorelaterad livskvalitet och tid sedan frakturen uppkom. Resultatet visade att kvinnorna med diagnostiserade vertebrala kompressionsfrakturer rapporterade sänkt hälso-relaterad livskvalitet upp till 18.9 år efter frakturen.

För att undersöka vad som prövats genomförde vi en systematisk litteratur översikt över interventioner som använts i syfte att stödja och underlätta dessa kvinnors vardag. Den visade att av cirka 8000 studier var det endast 7 som undersökt äldre kvinnor med en eller flera vertebrala kompressionsfrakturer och benskörhet. De flesta av studierna utvärderade effekterna av fysisk aktivitet på aspekter så som nivå av smärta och användning av analgetika, livskvalitet, fysisk funktion, psykologiska symtom och rädsla för fall. Analysen visade att det finns moderat belägg för att fysisk aktivitet förbättrar dessa olika aspekter. Det framkom också att det är svårt att generalisera effekterna av interventionerna bl. a på grund av den sårbara population och eftersom det är de med mindre symtom, som huvudsakligen deltar i studierna. Det kan därför antas att det finns ett mörkertal med kvinnor, med svårare symptom som inte finns representerade i studierna.

Avslutningsvis genomförde vi en studie baserad på djupintervjuer med 10 kvinnor, i syfte att försöka förstå upplevelsen av att leva med benskörhet och vertebral kompressionsfrakturer. Kvinnorna målade i sina berättelser upp en mörk bild av att leva i oförutsägbarhet, i en oberäknelig kropp, med oförmåga att finna stabilitet i sin tillvaro. De berättade att de levde i ständig rädsla och oro och att de tvingats lära sig nya strategier för att kunna leva med ryggsmärtan, som en ständig följeslagare.

Resultatet av denna avhandling visar att kvinnor med långvarig ryggsmärta har nedsatt fysisk förmåga med sämre hälsorelaterad livskvalitet men trots detta upplever sin vardag som hanterbar. Den fysiska hälsorelaterade livskvaliteten är fortsatt nedsatt 18.9 år efter att de ådragit sig en vertebral fraktur men genomförda interventioner med fysisk aktivitet visar på en viss förbättring av livskvalitet och fysisk mobilitet. Kvinnorna berättar om en vardag präglad av turbulens, osäkerhet och instabilitet men också en inre motståndskraft som hjälper dem att hantera sin vardag och därigenom hitta vägar framåt med smärta som följeslagare.

LIST OF STUDIES

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Svensson, H. K. Olsson, L-E. Karlsson, J. Hansson-Olofsson, E. Hansson, T. Rydberg Sterner, T. Alhner, F. Hörder, H. Skoog, I. & Falk, H. (2018).
Physical function, functional ability, sense of coherence, and health-related quality of life in 70-year old women living with intense long-term back pain – a population study of the 1944 cohort.
[Submitted]

II. Johansson, L*. Svensson, H. K*., Karlsson, J., Olsson, L-E., Mellström, D., Lorentzon, M & Sundh, D.
Decreased physical health-related quality of life - a persisting state for older women living with clinical vertebral compression fracture.
*** Contributed equally**
[In manuscript]

III. Svensson H K., Olsson L-E., Karlsson J., Hansson, T & Hansson-Olofsson, E. (2017) .
The effects of person-centered or other supportive interventions in older women with osteoporotic vertebral compression fractures - a systematic review of the literature.
Osteoporosis International, 28(9), 2521–2540.

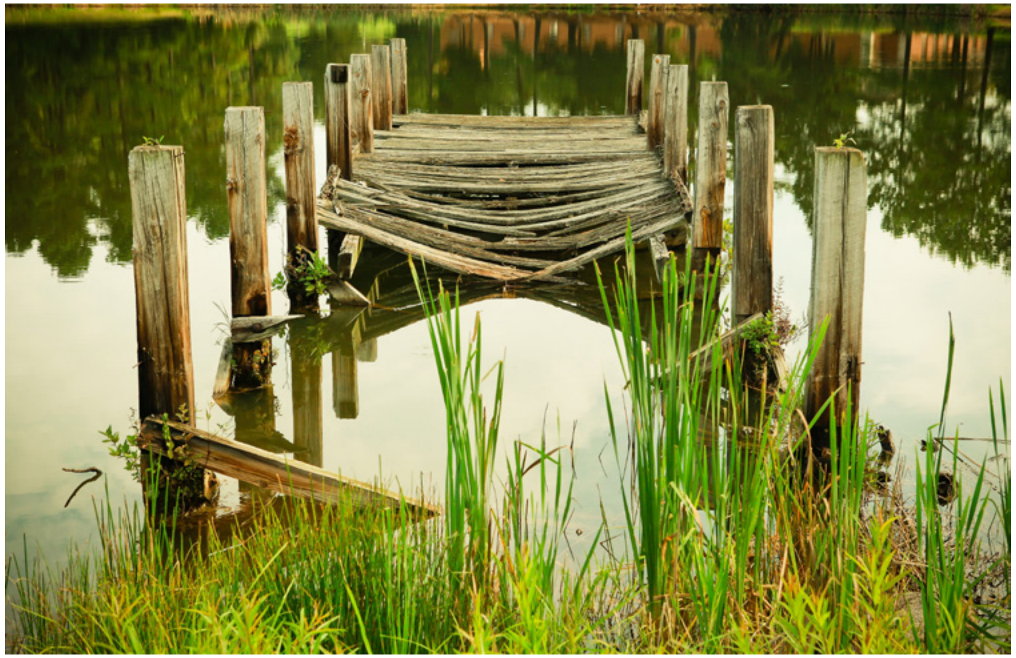
IV. Svensson, H. K., Olofsson, E. H., Karlsson, J., Hansson, T., & Olsson, L. E. (2016).
A painful, never ending story: older women's experiences of living with an osteoporotic vertebral compression fracture.
Osteoporosis International, 27(5), 1729-1736.

CONTENTS

ABBREVIATIONS

ADL	Activities of daily living
IADL	Instrumental activities of daily living
DXA	Dual-energy x-ray absorptiometry
BMD	Bone mineral density
BMI	Body mass index
VCF	Vertebral compression fracture
VFA	Vertebral fracture assessment
HRQoL	Health-related quality of life
SOC	Sense of coherence

INTRODUCTION



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INTRODUCTION

The global population is steadily becoming older and the number of persons over the age of 85 is estimated to reach 91 million by the year 2020; thereby increasing the number of people living with long-term conditions. Osteoporosis and subsequent vertebral compression fractures (VCF) are common in older adults, especially women, and often cause long-term back pain, resulting in reduced physical ability and an inability to perform daily activities. Based on current demographic projections, the health-care expenditure for patients suffering from osteoporosis and VCF will increase in the coming decades, provided that the age-specific prevalence remains constant.

Existing research essentially focuses on medical treatment and the evaluation of medical interventions. Older women suffering from long-term back pain are often neglected and have low priority in health-care. Knowledge relating to these women's life situation is sparse and this thesis therefore focuses on their experience of living with VCF and long-term back pain, reflected through a process of transition.

The vison of this research is to contribute to a comprehensive understanding of these women´s life situation, leading to the optimization of care efforts to support them in finding ways forward, with back pain as a fellow traveler.

01

BACKGROUND

1.1 Aging population

The proportion of older people worldwide is increasing and the global structural change to an aging population is being driven essentially by the progression of *"demographic transition"*, which refers to decreased reproductivity, reinforced by increased longevity (Population division (DESA/UN) 2000a). In 2015, 12% (901 million) of the world's population was over 60 years of age, which is estimated to increase to 1.4 billion by year 2030 and 2.1 billion by the year of 2050 (United Nation [UN], 2015, 2017). It is estimated that the number of people in the age-range over 80 years will increase by the year of 2050 to 379 million (Population divison [DESA/UN], 2000c). The WHO has estimated an increase in the number of people over 85 years of age from 14 million to 19 million by year 2020, with an additional intensification to 40 million by year 2050 (World Health Organization [WHO], 2017). This will increase the older-age dependency ratio, i.e. those of working age will be outnumbered by those being dependent (UN, 2017). In 2010, there were 26 dependent citizens per 100 within working age in the European region. This is expected to increase to 52 per 100 by 2050 (World Health Organization [WHO], 2002; Population divison [DESA/UN], 2000b).

Europe represents the world's oldest population with a mean life expectancy of 78 years from birth, with 25% of the inhabitants aged over 60 years (UN, 2017). In 2050, the number of people aged 60 years and over is projected to reach 2, 1 billion, constituting one third of the total population of Europe, and there will be the same proportion of people under 15 years of age as over 60 years of age. In 2015, the number of inhabitants over 80 years was 125 million, which will increase to 434 million by 2050, representing 28% of the European population according to the given projections. The current gender ratio within the age-range over 60 years is three men for every five women and, within the age group over 80 years two to five (UN, 2015, 2017; DESA/UN, 2000a, 2000c).

Sweden had a population of 9.8 million inhabitants in 2015 and it will increase to 11.9 million by 2050. The proportion of people over 60 will increase from 25.5% in 2015 to 29.6% by 2050, and for citizens in the age range of 80 with the percentage will increase from 5.1% in 2015 to 9.5% by 2050 (Fehlings et al., 2015; DESA/UN, 2000a).

"Epidemiological transition" refers to the evolutional alteration from infectious and nutritional diseases to a more prominent proportion of chronic degenerative and non-communicable conditions (UN, 2015, 2017; Fehlings et al., 2015). Suggested explanatory keys to this increase in longevity are a life-long reduction in exposure to chronic infectious diseases and inflammation causing organ damage (e.g. HIV) (DESA/UN, 2000a; Fehlings et al., 2015; UN, 2015, 2017; Crimmins & Finch, 2006; Bäckman, et al., 2016) and improvements in nutritional status (Barker, 2004), in addition to new and effective medical treatments (Rita Balistreri et al., 2014).

Wilkins (2001) described aging as *"a natural process, a time of wisdom and forthrightness, a time of changing priorities and new found freedom"* but also as *"a time of loneliness and uncertainty, and a time of deterioration and loss of independence"* (Wilkins, 2001a). Aging implies a reduction in health, with a higher prevalence of chronic and degenerative diseases, more dependence on others, lower economic status, increased isolation and reduced mental function (Chappell & Havens, 1980). Aging is also characterized by genetic molecular and cellular changes which, together with life style factors, enhance the risk of developing several pathologies such as cancer, diabetes, cardiovascular conditions and neurodegenerative diseases (López-Otin, Blasco, Partridge, Serrano & Kroemer, 2013). However, these biological changes are neither linear nor consistent and have a vague association with a person's chronological age and can therefore not be generalized. Disability might be described as the discrepancy between the intrinsic capacity and the ambient environmental requirements (World Health Organization [WHO], 2015).

The WHO purpose that the factor of a person's physical and mental health is dependent on life style behaviors, such as engaging in regular physical activity and refraining from smoking. However, social aspects, such as place of residence, neighborhood and communities with a supportive environment allowing the person to continue doing things that are important to him/her, also play a significant part in influencing healthy aging (WHO, 2002; WHO, 2015).

The experience of aging has been described as a sense of loneliness, which might be fueled by the loss of a partner, with a diminished and limited social network, a sense of being rejected and a distinct discrepancy between desired and factual social contact (Nicolaisen & Thorsen, 2014). Other studies have differentiated the sense of isolation from loneliness, where loneliness is a subjective consequence of the perceived absence of companionship and isolation is the effect of the absence of meaningful relationships in old age. Isolation may be either voluntary or involuntary; either way, it creates a sense of alienation from the world and the society of which they were once a part of, affecting both health perception and HRQoL (Dickens, Richards, Greaves & Campbell, 2011; Hawton et al., 2011).

Ebrahimi, Wilhelmson, Moore and Jakobsson (2012) describe the experience of frail aged perception on what is necessary to achieve harmony and balance to experience successful, productive aging. Intrinsic convictions of consistency and predictability that became noticeable were being able to master daily life in managing everyday tasks without the help of others, maintaining bodily functions to meet demanding activities or personal desires, the acceptance of the process of aging and a sense of life satisfaction. Extrinsic aspects that became salient to maintaining a positive outlook on aging were being regarded as a worthy and competent person and to being able to be involved as part of a community despite deficiencies and regardless of older age (Ebrahimi, Wilhelmson, Moore & Jakobsson, 2012)

The experience of aging also includes encountering benign or malignant ageism (Nicolaisen & Thorsen, 2014). Ageism can be defined as the subtle, yet unmistakable, way in which older adults are valued and discriminated by society and the healthcare system. (Makris et al., 2015). Many older persons are subjected to ageist attitudes due to their advanced age, assuming that they are physically and mentally restricted, vulnerable and dependent. This might be perceived by the person as being futile and unfit for treatment, a way of thinking that healthcare policies need to reduce rather than reinforce (WHO, 2015; Eriksson, 2008). Research from The Center for Aging and Health, University of Gothenburg (AgeCap), has been able to show a significantly higher level of independence with regard to ADL, as well as engagement in leisure activities between two cohorts of 75 year olds, born 30 years apart (Falk et al., 2014). This challenges the stereotypical notion that everyone of advanced age is in need of healthcare and support, instead implying that older persons today enjoy a high level of independence, cognitive ability, e.g. logical reasoning and spatial ability, better fitness, travel more and have socially active lives and need to be regarded as capable individuals (Eriksson, 2008; Falk et al., 2014; Karlsson, Thorvaldsson, Skoog, Gudmundsson & Johansson, 2015; Thorvaldsson, Karlsson, Skoog, Skoog & Johansson, 2016; Skoog, 2004).

In western societies, health-care practices were developed in an era in which acute infectious diseases were the predominant concern. However, these practices have proven to be inadequate and ineffective in meeting the needs of those with long-term conditions, where the primary focus is to restore and maintain the persons' function and wellbeing, rather than cure (World Health Organization/Nolte & McKee,2008; WHO, 2002). Despite this clear discrepancy in point of departure, most health-care systems throughout the world are still trying to manage long-term conditions using acute health-care strategies (Corrigan, Donaldson & Kohn, 2005; Baker, 2001). Consequently, health-care systems throughout the world are facing a critical challenge in being able to adapt and be flexible in their consultations relating to the complex healthcare need, of a large and growing population of older persons with varying levels of disability and age-related chronic conditions (World Health Organization, 2010; WHO, 2008; Bäckman et al., 2016; Fehlings et al., 2015). It might be suggested that, for the human development, aging could be seen as a success but, for the medical disability system, it is seen as a failure. Within different care settings, older people are often neglected and viewed as patients with unclear, undefined symptoms, often regarded as age-related. So, to be able to care for the majority of the patients visiting our hospitals, there is a need for multi-professional healthcare teams working with people of advanced age. By addressing both care needs and disability, but also with the purpose of maintaining a subjectively meaningful experience of aging, this might be a way forward and beyond (Ebrahimi, Wilhelmson, Eklund, Moore & Jakobsson, 2013; Edvardsson & Nay, 2009; World Health Organization, 2016; WHO, 2008).

1.2 Back pain

The clinical definition of back pain is based on the permanence of the experience of pain after its onset; acute back pain (< 4-6 weeks), sub-acute back pain (6-12 weeks) and persistent or long-term back pain (> 12 weeks) (Van Tulder et al., 2006; Bussiéres, Taylor & Peterson, 2008). In a meta-analysis of the projection of back pain, Costa et al. (2012) reported a considerable decrease in pain experience within the first four to six weeks in patients with both acute and sub-acute back pain. On the other hand, patients with a diagnosis of long-term back pain, experienced a slower improvement within the first weeks and continued reporting pain-induced disability up to one year after onset (Costa et al., 2012). In Europe, the estimated lifetime prevalence of back pain is 84% within the population, with 44-78% of the affected individuals suffering several recurrences during their lifetime (Airaksinen et al., 2006). Within the older segment of the population, nearly 23% report long-term back pain and 12% describe the back pain as physically disabling (Burton et al., 2006). However, assessments of the prevalence and incidence of back pain are difficult due to variations in classification, definition and terminology within different countries and contexts (Van Tulder et al., 2006). Physical disabilities, which previous studies have reported as prominent, have a strong association with long-term back pain with impaired balance, slower gait speed, and reduced physical endurance and walking ability together with a sense of fear of falling and depression (Clark, Gooberman-Hill & Peters, 2016; Hübscher, Vogt, Schmidt & Fink, 2010; Braden et al., 2012; Lihavainen et al., 2010; Makris, Fraenkel, Han, Leo-Summer & Gill, 2014a, 2014b, 2014c; Tomita et al., 2015).

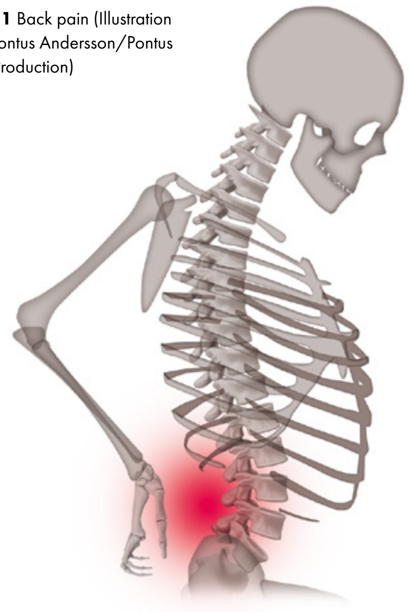


Fig. 1 Back pain (Illustration by Pontus Andersson/Pontus Art Production)

Risk factors for developing long-term back pain involve poor muscular strength and physical fitness, smoking habits and excessive alcohol consumption, as well as psychosocial aspects (e.g. stress, anxiety and depression) but also strenuous physical work and long time periods of sedentary lifestyle (Van Tulder et al., 2006; Akadeniz et al., 2009; Schmelzer et al., 2016). Majid & Truumees (2008) also pointed out the association between long-term back pain and educational level, weight, age and gender, whereas socioeconomic aspects are seen as weaker predictive factors of the development of degenerative disorders, but they are more prominent in relation to the onset of long-term back pain and disability in general (Majid & Truumees, 2008).

The causes of long-term back pain are mostly nonspecific. About 5-15% of the onset of back pain can be derived from different aspects of disc degeneration, malignancies, infections or inflammatory conditions (Van Tulder et al., 2006; Enthoven et al., 2016). However, in the population of older post-menopausal women, the most common and prominent reasons for long-term back pain are VCF caused by osteoporosis or degenerative disorders like spondylosis, spondylolisthesis and spinal stenosis (Enthoven et al., 2016; Clark et al., 2016).

1.3 Osteoporosis

Dr Nicholas S. Ransohoff reported on the radiographic appearance of a fractured forearm in the Annals of Surgery in 1929: *"…after the next set of films was taken it was noticed upon closer study of this first one that some structural change was taking place in the distal fragment. This showed itself as a peculiar mottling of the bone more marked distally, which, for want of a better term, we shall call "osteoporosis". The corticalis was well marked and had a very slightly honey-combed or moth-eaten appearance"*(Ransohoff, 1929).

Osteoporosis is defined as a skeletal disease, characterized by low bone-mineral and the micro architectural deterioration of bone tissue, and leading to high morbidity and mortality through a subsequent increase in bone fragility and susceptibility to fracture, notably of the hip, forearm, vertebrae and humerus, with low forces required (Fig. 2) (Word Health Organization, 2003; Johnell & Kanis, 2006; World Health Organization, 2004; Hagenfeldt et at., 2003). It has an asymptomatic and progressively deteriorating disease trajectory and is referred to as a silent disease, given that most individuals are unaware of the diagnosis until the onset of the first fracture (Hannafon & Cadogan, 2014; Hagenfeldt et al., 2003; Hallberg, Ek, Toss & Bachrach-Lindström, 2010; Hansen, Konradsen, Abrahamsen & Pedersen, 2014). Significant risk factors in developing osteoporosis are advanced age, physical inactivity and immobilization, long-term medical treatment, such as glucocorticoids, lithium, methotrexate or loop diuretics, low body weight, a family history of fracture, tobacco use and excessive alcohol consumption (O´Connor, 2016).

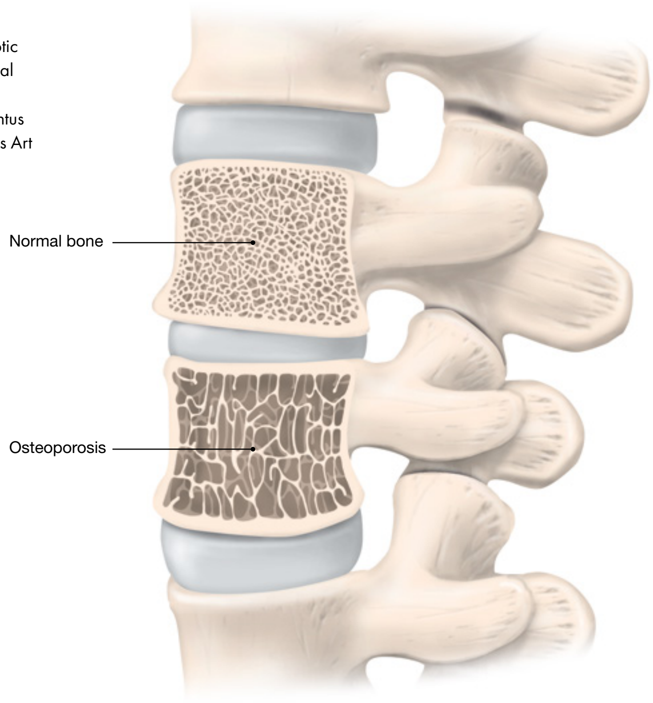


Fig. 2 Osteoporotic bone versus normal bone structure (illustration by Pontus Andersson/Pontus Art Production)

Osteoporosis is a growing public health problem due to current epidemiological projections, and it is more commonly found in women, thus making women more susceptible to fragility fractures than men (Johnell & Kanis, 2006). The growth period is crucial to skeletal development, resulting in larger, stronger bones in males than in females. Estrogen deficiency after menopause is strongly associated with rapid resorption and the loss of bone density, which contrasts with the gradual decline in estrogen and bone mineral density seen in aging men. Although estrogen deficiency is more pronounced in women, it also plays a major role in the pathogenesis of osteoporosis in men (Matsushita & Wakatsuki, 2015). There might also be an explanation in that women live longer than men and therefore have a longer period of being exposed to age-related risk factors for developing osteoporosis and subsequent fractures (Hernlund et al., 2013).

Osteoporosis accounts for almost 1% of the global burden of non-communicable conditions, imposing a significant disease burden on society (Johnell & Kanis, 2006). By 2010, it was estimated that 22 million women and 5.5 million men within the European Union were suffering from osteoporosis, with increase in the subsequent fracture risk (Holroyd, Cooper & Dennison, 2008; Hernlund et al., 2013). In Scandinavia, women at the age of 50 years run a three to four time higher risk than men of developing osteoporosis and the same risk applies to one in every three women in the age range of 70-79 years (Hagenfeldt et al., 2003). The reason why Europe and Scandinavia have a higher prevalence and incidence of osteoporosis could be explained by a combination of environmental and genetic factors (Holroyd et al., 2008). Several hypotheses on the effect of socio-economic prosperity in relation to reduced levels of physical activity have been formulated, as well as low levels of sunlight resulting, in the lack of conversion of endogenous vitamin D (Hernlund et al., 2013).

Against the background of the demographic population changes with increased life expectancy, Sweden and other industrialized countries are facing a growing number of older people suffering from osteoporosis, with not only subsequent personal consequences but also a considerable economic burden (Hannafon & Cadogan, 2014; Jahelka et al., 2009). A report in 2010 on the prevalence and incidence of individuals aged over 50 years suffering from osteoporosis in Sweden showed that approximately 114,000 men and 410,000 women suffered from osteoporosis (5.6% of the total population), with a health-related costs estimated to 13 billion SEK each year. In Sweden, an increase in the number of patients treated for osteoporosis could generate a fracture-related cost reduction of 270 million SEK each year (Svedbom et al., 2013; National Board of Health and Welfare, 2012). One crucial public-health issue is to prevent or postpone osteoporotic fractures, given that late-life activity limitation is one of the central components, fueling increased societal and health-related costs (Van Houwelingen et al., 2014). However, research has shown that only 20% of those affected by a fragility fracture receive osteoporotic treatment (Hannafon & Cadogan, 2014) and, in Sweden 2010, there was a 72% treatment gap between those eligible for treatment and those actually treated (Hernlund et al., 2013). A critical challenge facing health-care systems around the world is how to tackle these complex and costly care needs of people suffering from osteoporosis (Akadeniz et al., 2009).

Since the disease itself is asymptomatic, the diagnosis of osteoporosis is often determined after the person has suffered his/her first fragility fracture and has undergone dual-energy x-ray absorptiometry (DXA). The DXA provides bone mineral density (BMD) values in g/cm2, mostly measured in the spine and hip, but there are also other procedures such as using peripheral tests, tests measuring the lower arm, wrist, finger or heel (National Osteoporosis Foundation [NOF], 2018; Hagenfeldt et al., 2003). In 1994, the World Health Organization (WHO) formulated a guiding range in terms of t-scores of BMD; values of <-2.5 SD were viewed as osteoporosis, values between -2.4 SD and -1.0 SD were defined as osteopenia, and values above -1.0 SD were seen as normal bone density (Table 1) (Kanis, Melton, Christiansen, Johnston & Khaltaev, 1994; Kanis, 1994).

Table 1. BMD specified by standard derivation according to WHO t-score.

	BMD
Normal	- 1
Osteopenia	<-1 to -2.5
Osteoporosis	< -2.5

In 2004, the WHO developed a fracture risk algorithm (FRAX) to rationalize and make the screening process more efficient. FRAX screening tool predicts a 10-year risk of a major osteoporotic fracture based on gender, age, BMI, previous fractures, family history of hip fracture, tobacco use, alcohol consumption, use of glucocorticoids, diagnosis of rheumatoid arthritis and BMD (Varacallo & Fox, 2014; Cosman et al., 2014; WHO, 2004). There is a dissonance in the existing recommendations depending on whether women between the ages of 50-64 should be routinely screened for osteoporosis or osteopenia, regardless of whether risk factors are present (O´Connor, 2016). The National Osteoporosis Foundation (NOF) recommends bone density testing if the person is female, post menopause, over 65 years of age or has decreased significantly in height (NOF, 2018) and The Swedish National Board of Health and Welfare endorses DXA measurement after the assessment of fracture risk using FRAX (National Board of Health and Welfare, 2012).

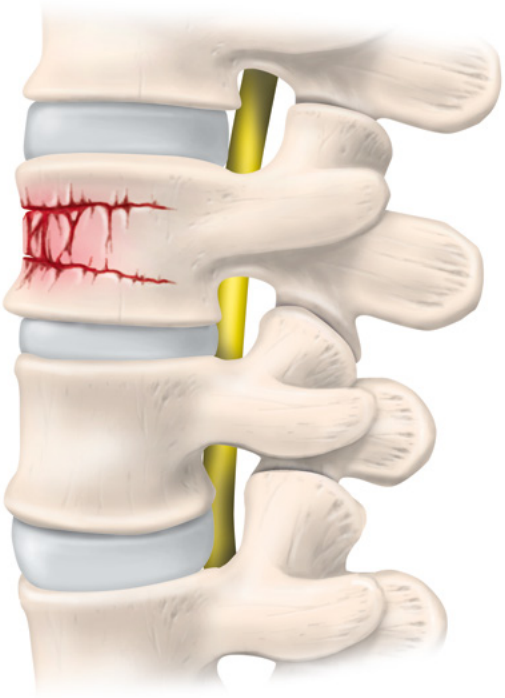
The pharmacological treatment of osteoporosis is well studied and there is strong evidence of its positive effect. The National Osteoporosis Foundation recommends that osteoporotic treatment should be offered to all postmenopausal women with a history of fracture (hip or spine) and a DXA verified bone density of -2.5 or less, but it should also be considered when the results show DXA verified osteopenia (t-score between -1.0 and -2.4) and a 10-year fracture risk of > 3% assessed by FRAX (O'Connor, 2016). There are different pharmacological treatments designed to inhibit bone resorption or promote new bone growth to improve bone mineral density in persons with osteoporosis (Liu, Yang, Kong, An & Wang, 2015). Bisphosphonate (e.g. Alendronate®, Risedronate® and Zoledronic acid®) is recommended as the first-choice therapy and has been shown to reduce the hip and VCF risk by up to 50% (O´Connor, 2016).

The choice of agent in the treatment plan should be based on the location of fracture, site of measured low bone density, side-effects, contraindications, such as comorbidity or polypharmacy and the patient's likelihood of adherence (O´Connor, 2016; Varacallo & Fox, 2014). There is controversy about the use of basic supplements of calcium and vitamin D in preventing further osteoporosis development. The Swedish National Board of Health and Welfare concludes that treating women without verified deficiencies has no scientific support and has entails an increased risk of cardiovascular complications (National Board of Health and Welfare, 2012). Other studies have shown a decrease in further fracture risk when these supplements are used as secondary prevention after the first fracture has occurred, but they are also widely used in many health-care contexts within the primary prevention treatment plan, i.e. before the first fracture occurs (Tella & Gallagher, 2014; Maeda & Lazaretti-Castro, 2014; Hannafon & Cadogan, 2014). Non-pharmacological primary prevention treatment for osteoporosis involves regular physical activity involving, for example, resistance and weight-bearing exercises, which increase muscular mass, or balance exercises that reduce the risk of falls. In addition to recommendations of a physically active lifestyle, aspects such as smoking habits and alcohol consumption should be addressed, as well as a reduction in or the discontinuation of treatment with drugs that reduce BMD (Black & Rosen, 2016).

In reality, many patients with osteoporosis, or running a high risk of developing the condition, are often overlooked in primary care settings (Maeda & Lazaretti-Castro, 2014). The majority of patients that run the highest risk of developing low bone density have co-morbidities such as heart failure, obstructive pulmonary disease or diabetes, which become the main focus, leaving the possible underlying osteoporosis going unnoticed (Varacallo & Fox, 2014). Research has shown that only 27% of women at risk and aged between 66-70 years undergo DXA testing to establish the diagnosis, while the corresponding figures is only 16% between the ages of 81-85 years (Dell & Greene, 2010; Varacallo & Fox, 2014). The lack of an established protocol for identifying patients at risk has meant that the most common way of establishing the diagnosis is when a fragility fracture occurs. Hannafon & Cadogan (2014) point out the responsibility of the nursing profession in the primary care setting to have a clearly defined position in order to promote awareness and mediate guidelines and recommendations for screening patients at risk in order to develop individualized care plans and maximize the effectiveness of treatment (Hannafon & Cadogan, 2014). The development of different systematic screening tools, such as FRAX, should be able to close the care gap in osteoporosis management and minimize the risk of patients falling through the cracks and not having their osteoporosis diagnosed and treated (Green & Dell, 2010).

1.4 Vertebral compression fracture

Fig. 3 VCF (Illustration by Pontus Andersson/Pontus Art Production)



In 2010, osteoporosis caused more than 8.9 million fractures annually worldwide and over 490,000 of those fractures occurred in Europe, estimated at an annual cost of 37 billion euros (Kammerlander et al., 2014). The WHO has projected that, during the next 50 years, the annual number of fragility fractures will increase threefold worldwide (WHO, 2004). The VCF is the third most common fragility fracture, estimated to account for approximately 1.4 million fractures worldwide at a cost of 1,8 billion euros (Kammerlander et al., 2014; Johnell & Kanis, 2006; Clark et al., 2016; Hagenfeldt et al., 2003; Hansen et al., 2014). At the age of 50 years there is a 15% risk for women and 9% risk for men of suffering a VCF due to osteoporosis (Hagenfeldt et al., 2003; Cauly et al., 2007). Twelve per cent of all postmenopausal women have at least one VCF, and 58% of them have long-term back pain (Clark et al., 2016; Airaksinen et al., 2006). Studies show a higher incidence in men between the ages of 50-55 years, but the incidence increases significantly in women after the age of 60 years (Schousboe, 2016). The annual incidence of VCF in Europe within the age range of 50-79 years was estimated to reach 1.1% in women and 0.6% in men (Kammerlander et al., 2014; Sıklık & ve Siddeti, 2013; Felsenberg et al., 2002). The incidence is higher in Sweden, 16,000 fractures of a total of 107,000 new fractures each year constitute VCFs. In Sweden, there is a 2-2.5 higher risk within the female population compared with the male population of sustaining a VCF (Hernlund et al 2013; Felsenberg et al 2002). Differences between parts of the world and health-care contexts might be explained by differences in diagnostic methods and local guidelines for screening (Schousboe, 2016). Based on current demographic projections, the already enormous cost of VCF and the suffering of those afflicted (Schousboe, 2016) will increase in the coming decades, provided that the age-specific prevalence remains constant (UN, 2017).

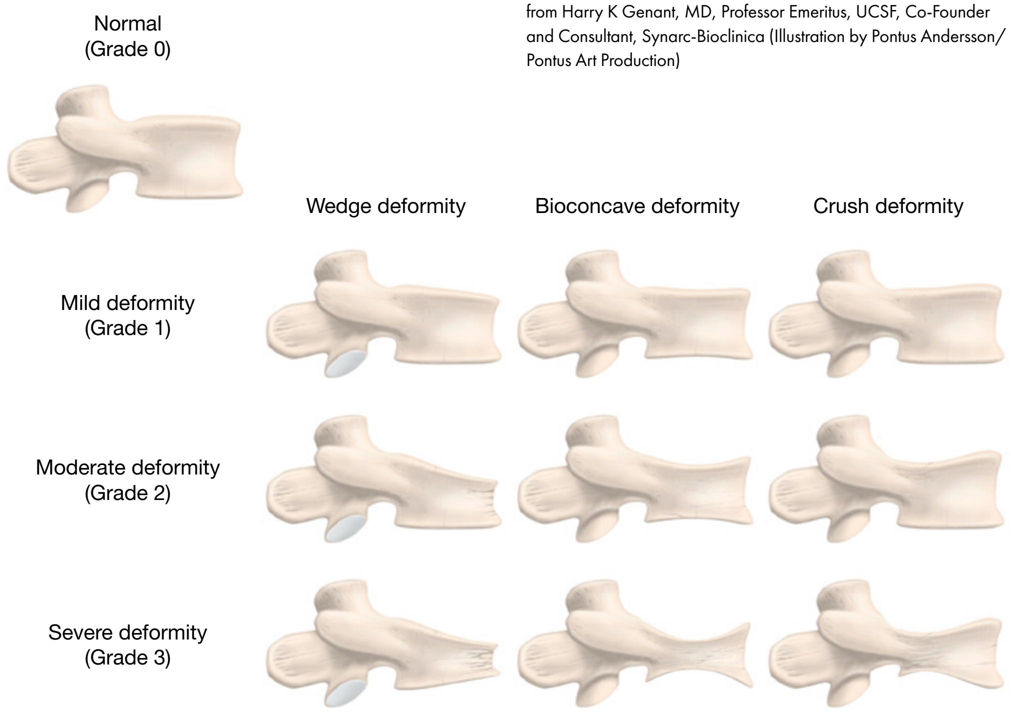


Fig. 4 Model for semi-quantitative technique. Used with permission from Harry K Genant, MD, Professor Emeritus, UCSF, Co-Founder and Consultant, Synarc-Bioclinica (Illustration by Pontus Andersson/ Pontus Art Production)

A VCF caused by osteoporosis refers to a fracture through the collapse, compression or wedging of a vertebral body caused by low-energy force, which would normally be insufficient to cause a fracture of the bone (Fig. 3) (Jonell & Kanis, 2006; Clark et al., 2016; Varacallo & Fox, 2014). Studies have shown that approximately 50% of all VCFs occur without a fall or obvious reason, as different from the fractures of the hip where 90% can be linked to a fall (Schousboe, 2016). Factors that have been proposed to affect the fracture risk are heredity, female gender, age, early menopause, tall stature and previous fracture regardless of location (Kilincer, et al., 2013). The most commonly used assessment is the DXA with Vertebral Fracture Assessment (VFA) or x-ray and the assessment of VCF deformities is made using a semi-quantitative technique demonstrating a decrease in the height of the vertebrae (15-20%) with a wedge, biconcave or crush feature (Fig 4) (Genant, Wu, van Kuijk & Nevitt, 1993).

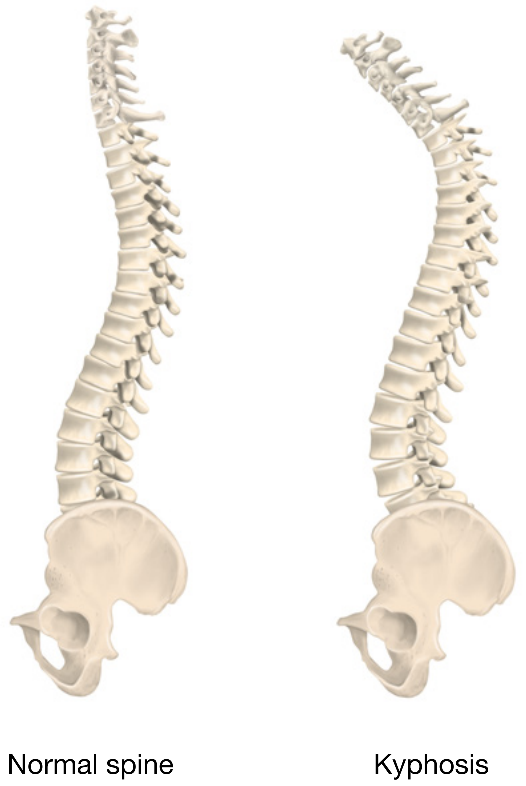
The wedge deformity is the most frequent and it is mostly commonly present between Th12 and L1, but it might affect other locations of the spine from T9 to L2 (Schousboe, 2016; Physical Activity the Prevention and Treatment of Disease (FYSS), 2016; Kilincer, et al., 2013; Kammerlander et al., 2014). The risk of incurring a new VCF during the first year after an initial fracture increases up to four to five times and there have been reports of increases in mortality rate during the first year from 6.5% up to 15% (Goldstein, Chutkan, Choma & Orr, 2015).

We know that the pain intensity of a VCF reduces physical activity and thereby increases disability which will in turn accelerate bone mineral loss, leading to further osteoporosis, i.e. disuse osteoporosis, and increase the risk of a new VCF. This pain-induced inactivity will also affect the musculature stamina and strength, resulting in muscle hypotrophy and weakness, factors which will multiply the risk of falls with a subsequent risk of new fractures (Kammerlander et al., 2014; Suzuki, Ogikubo & Hansson, 2008; Aoyagi & Sheprad, 2010; Svedbom et al., 2013). The physical disability is also fueled by changes in bodily constitution with increased thoracic kyphosis and lumbar lordosis (Fig. 5). As the deformity worsens the para spinal muscles contracts to maintain posture and uphold the spine in an upright position, which in turn places an increased load on the vertebral bodies and escalates the deformity of the back. This vicious circle progressively limits function and increases future fractures through impaired balance with an increased incidence of falls (Varacallo & Fox, 2014).

In addition to back pain, constant or activity induced, research has also shown other consequences associated with VCF, such as impaired pulmonary function due to kyphosis, fatigue, rapid satiety during meals with weight loss, deep vein thrombosis, low self-esteem and emotional and social problems (Kammerlander et al., 2014). Several studies have shown a significant decrease in quality of life, from both a health perspective and an existential point of view. They show significantly lower health-related quality of life

(HRQoL) in women with VCF compared with age-matched peers with regard to both physical and mental components (Sanfélix-Genovés, Hurtado, Sanfélix-Gimeno, Reig-Molla & Peiró, 2011; Bergerow et al., 1999; Rostom, Allali, Bennani, Abouqal &Hajjaj-Hassouni, 2012; Hall, Criddle, Comito & Prince, 1999; Papaioannou et al., 2006; Aoyagi & Sheprad, 2010a; Aoyagi, Park, Park & Sheprad, 2010b; Lips & van Schoor, 2005; Suzuki, Ogikubo & Hansson, 2009; Hallberg, Bachrach-Lindstrom, Hammerby, Toss & Ek, 2009).

Fig. 5 Kyphosis of the spine
(Illustration by Pontus Andersson/
Pontus Art Production)



However, for several reasons, many VCFs are missed or neglected and less than one third of those affected come to clinical attention, underestimating the true prevalence as well as the incidence (Clark et al., 2016; Kanis et al., 2004; Kammerlander et al., 2014; Varacallo & Fox, 2014; Hagenfeldt et al., 2003; Schousboe, 2016; Sosa et al., 2015). This might be due to diffuse symptoms of the fracture that will be interpreted as an age-related unspecified differential diagnosis (Tosteson et al., 2001), methodological problems (Waterloo et al., 2013) or vague and indistinct areas of responsibility within the presiding healthcare context (Kanis et al., 2004; Varacallo & Fox 2014; Kammerlander et al., 2014; Megale et al., 2017), leading to low rates of referral to the appropriate osteoporosis facilities (Varacallo & Fox, 2014). Since a previous VCF is one of the best predictor of future fracture risk, the underdiagnoses of VCF results in the loss of vital information in the strategy of establishing preventive measures (Kilincer, et al., 2013). It is therefore important to identify all fractures, symptomatic as well as asymptomatic (Varacallo & Fox, 2014; Schousboe, 2016). Research has shown that most VCFs are identified as an incidental finding when the individual undergoes radiographs for other reasons. However, the identification of a VCF is treated as just an incidental finding and is not reported or managed by means of an osteoporotic assessment and treatment (Kammerlander et al., 2014).

It was previously believed that VCF and its subsequent consequences, of back pain, were self-limiting and subsided within weeks or a few months. However, this relatively positive view was rejected by researchers who have proved exact opposite. One study observing women and men during the first year after an acute VCF was able to establish that most persons experienced the fracture as the beginning of a long-lasting, severely painful and disabling condition (Suzuki et al., 2008; Suzuki et al., 2009; Hallberg et al., 2009). The severity of pain is associated with the level of fracture as well as the appearance of the fracture, i.e. wedge, biconcave or crush, and the decrease in height of the vertebrae (Schousboe, 2016) and the pain becomes worse when sitting up or standing and is mitigated when lying down (Kammerlander et al., 2014).

In Sweden, and most other western countries, the recommended treatment after an acute VCF comprises early mobilization, combined with pharmacological pain management (advantageously opioids and muscle relaxants) and anti-resorptive bone medication (bisphosphonates) (Kammerlander et al., 2014). However, 75% of patients with VCFs seeking emergency care are often sent home without appropriate or sufficient pain medication and without any rehabilitation plan or supportive follow-up within the primary care context (Landis, 2005; Suzuki et al., 2008; Beaton et al., 2012; Freedman et al., 2008; Hallberg et al., 2010; Paier, 1996; Papaioannou et al., 2006; Yoon et al., 2014).

Surgery as a way to treat VCF is associated with several difficulties due to the low bone density in adjacent vertebrae related to the underlying osteoporosis (Schousboe, 2016). A meta-analysis of the current evidence relating to the use of two different surgical techniques; percutaneous vertebroplasty, introduced by Gailbert in 1984, and percutaneous balloon kyphoplasty, first performed in 1988, showed a significant reduction in pain-levels and an increase in HRQoL, as well as an improvement in physical ability (Shi-Ming et al., 2015; Kammerlander et al., 2014). However, other studies indicate the contrary and report that the invasive treatment alternative has been shown to be less promising than anticipated in VCF management due to side-effects and postoperative complications (Buchbinder et al., 2009; Kallmes et al., 2009). In 2012, the National Board of Health and Welfare in Sweden specified that there is no indication for surgery in the management of VCF due to the moderate or low quality of evidence relating to its effect on pain, HRQoL and physical function (National Board of Health and Welfare, 2012). Since the benefits of surgical treatment lack practical evidence, the disabling pain caused by the VCF will develop into a chronic condition that interferes with daily activities and threatens the individuals' independence, making VCF a major public-health issue (Cauly et al., 2007; Suzuki et al., 2008; Hallberg et al., 2009).

There are differing opinions with regard to the use of special back orthoses in patients with VCF. Studies have shown a decrease in the levels of pain and an increase in HRQoL after using an orthosis for 2 h per day in six months (Gerdhem, 2013), but, concerns about the hypotrophy of back muscles and the increased instability of the spine when the treatment period is completed have been raised and emphasized (Kammerlander et al., 2014).

Early mobilization is crucial in the care and rehabilitation of a geriatric patient with VCF, together with adequate pain medication (Kammerlander et al., 2014). However, there are several challenges in the rehabilitation of older persons with VCF (Buchbinder et al., 2009; Kallmes et al., 2009). Although the individual motivation and intrinsic determination for rehabilitation might be present, advanced age, along with co-morbidity, adds to their already reduced ability for physical rehabilitation. This is also one explanation for the high risk that older, frail individuals will descend into a trajectory of impaired physical state, as well as their general health status after a fracture (Kammerlander et al., 2014).

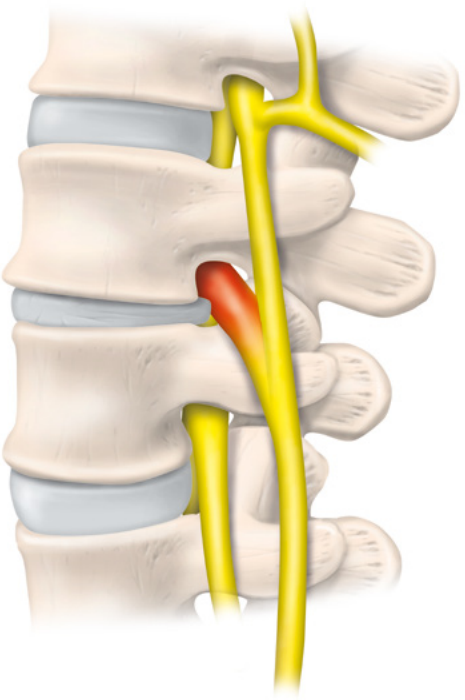
However, research has shown the beneficial effects of multicomponent exercise programs, such as posture, balance and muscle strengthening exercises to reduce the levels of pain and prevent future falls with subsequent fracture risk (Giangregorio et al., 2014). Most studies of VCF in old age focus on treatment effects, different experimental surgical procedures and the probability of rehabilitative interventions (Burke, Franca, Meneses, Pereira & Marques, 2012; Qvist, Bergström, Kronhed, Karlsson & Forss, 2011; Blasco et al., 2012; Schröder, Knauerhase, Kundt & Schober, 2012). Research has shown the benefits of interdisciplinary management to ensure quality, prevent complications and, depending on the patients' individual preferences and needs, optimize medical treatment and rehabilitation (Kammerlander et al., 2014). Without sufficient pain relief and organized supportive follow-up, initiating and pursuing the development of a healthy transition towards a renewed phase of stability and acceptance may be unmanageable (Landis, 2005).

1.5 Degenerative disc disorder

Degenerative disc or spinal disorders lack a standardized definition and are therefore difficult to assess with regard to prevalence; estimates vary between 12% and 56% (Battié et al., 2014; Malik, Choen, Walega & Benzon, 2013; Raj, 2008). Like those affected by VCF, there is a small group of individuals who come to clinical attention and undergo radiographic assessment in order to establish a diagnosis (Kalichman & Hunter, 2008; Ailon et al., 2015). Degenerative disc disorder is more common among the female population and is present in 19% of women reporting back pain, which is estimated to increase to 23% by 2060 due to a aging population (Clark et al., 2016; Airaksinen et al., 2006; Ailon et al., 2015; Kalichman, Guermazi, Li & Hunter, 2009).

Degenerative disc disorder is mainly age related, but research has also shown a dominant effect of heredity, explaining 74% of the variance within the adult population (Battié, Videman & Parent, 2004; MacGregor, Andrew, Sambrook & Spector, 2004). It is characterized by the dehydration (loss of aggrecan and water) of the intervertebral discs which, together with decreased permeability in the endplates of hyaline cartilage, leads to less nutrient and a decrease in height of the discs (Fig. 6). This causes a subsequent reduction in the intervertebral space with increased pressure on ligaments and joints that may cause the instability and malalignment of the spine with spondylolisthesis and scoliosis, leading to thoracic kyphosis (Fehlings et al., 2015; Ailon et al., 2015; Wilmink, 2011). The narrowed spinal canal also decreases the flow of cerebrospinal fluid and therefore increases the venous pressure and might cause edema (Schönström, Bolender, Spengler & Hansson, 1984; Fehlings et al., 2015). It is most commonly found in the lumbar spine, level L1-L4, and is graded based on three types (I, II, III) of severity (Tenne, Mcguigan, Besjakov, Gerdhem & Åkesson, 2013; Miller, Schmatz & Schultz, 1988).

Fig. 6 A degenerative disk (Illustration by Pontus Andersson/ Pontus Art Production)



The onset of pain in the case of a degenerative disorder is slow and discrete over time, in line with the gradual deterioration in the stability of the back. The pain is described as agonizing and constant and has a tendency to radiate into the neck or legs, but it subsides when the person is active and moving (Clark et al., 2015).

There are several surgical techniques, i.e. spinal fusion surgery, disc arthroplasty or posterior dynamic stabilization, to restore spinal alignment and decrease pain, decompress neural features, achieve fusion and minimize complications (Taher et al., 2012). However, for those with mild and non-progressive symptoms conservative non-surgical treatment is recommended. The treatment comprises physical therapies, which mainly address core strength and endurance, together with analgesics in combination with anti-inflammatory therapies (Ailon et al., 2015). New treatment options, e.g. oral glucosamine and chondroitin, cell-based therapies and disc implantation, have been developed during the past decade and show promising effects on degenerative disc disorder. However, there is still uncertainty in terms of effects and needs to be fully evaluated (Raj, 2008).

Differentiating VCF and degenerative disc disorder

One significant difference between degenerative disc disorder and VFC is the debut of pain. The onset of pain associated with a VCF is instantaneous and abrupt, whereas the progression of pain accompanying a degenerative disc disorder is more gradual and unobtrusive. Individuals affected by VCF experience more relief while lying down, whereas those with degenerative disc disorder usually experience an alleviation when active and moving. The VCF is less prone to cause radiating pain, whereas degenerative disc disorders more frequently tend to cause radiating pain into the arms and legs. The sense of pain also diverges in that the degenerative disc disorder is reported as excruciating and continuous whilst VCFs cause discontinuous, crushing and exhausting pain (Clark et al., 2016).

THEORETICAL FRAMEWORK

02

02

THEORETICAL FRAMEWORK

2.1 Illness versus disease

Illness is a person's experience of bodily changes and perceived symptoms, whereas disease is the biomedical definition that health-care practitioners postulate in recasting the illness, in terms of theories of disorder (Kleinman, Eisenberg & Good, 1978; Kleinman, 1988). According to Eisenberg, illness can be defined as *"the experiences of disvalued changes in a state of being and in a social function"*, whereas disease is *"abnormalities in the structure and function of the body's organs and systems"* (Eisenberg, 1977). Illness is based on individual experience and understanding of the body within a social and cultural context, while disease is valued within the scientific paradigm of modern medicine (Eisenberg, 1977). Consequently, the distinction between illness and diseases is essential in order to understand how pathological processes might affect body and mind of a person, but both perspectives needs to be represented.

The experience of illness presents itself in the lived body. It unsettles and questions our sense of self, as well as our existential preunderstandings and aspects of everyday life, such as taking every new day for granted or understanding that life does not last forever. Bodily changes, outside our control and understanding, affect an essential part of our selves but also the subjective core in which we experience, understand and act. Good et al. described the experience of illness as a loss of faith in one's own body and that existential parts taking the world for granted become lost (Good 1994). A sense of illness is followed by feelings of alienation from others, as well as being detached from everyday life, putting life and identity on hold, creating uncertainty and a threat of loss of control (Charmaz, 1997). Former normal daily activities, plans and social interactions are discarded and replaced by intrusive symptoms and medical undertakings.

2.2 Transition theory

Significant events or changes in a person's life situation lead to passages between phases in space and time, i.e. transitions between different positions in a life continuum. However, not all changes necessarily lead to a transition, but all transitions involve changes, i.e. the process of transition is both the result of change but also what generates change. This process transpires over time and, in order to capture the multidimensionality and generic components of the health and illness process, a middle-range theoretical framework of transitions was formulated by Meleis et al. in 2000, based on the original framework (Chick & Meleis, 1986). The theory was constructed from qualitative nursing studies within different contexts that used the original framework as a starting point, with a feministic approach. By using both inductive and deductive reasoning, Meleis et al. (2000) identified additional components incorporated into the expanded framework (Meleis, Sawyer, Im, Messias & Schumacher, 2000).

The process of a transition should be a dynamic progression comprising three phases: firstly, the initial life change, secondly, a phase of uncertainty and distress and, thirdly, leading to a phase of balance and acceptance that ends in an identifiable end-point. The theory defines different characteristics that determine whether the transition will result in a positive or/and healthy experience or a negative or/and unhealthy transition, leading to vulnerability and risk of illness. It comprises three aspects of the nature of the progress in transition (i.e. types, patterns and properties), transition conditions (i.e. facilitators and inhibitors) and patterns of response (i.e. process and outcome indicators).

The nature of a transition might be developmental and situational, relating to health and illness, or organizational. At the same time, ongoing transitions may be single or multiple, sequential or simultaneous and be related or unrelated to one another. Properties guiding the transitional progress include the person's awareness of and engagement in the upcoming health or illness situation, together with the ability to adapt to changes in identity and roles, as well as relationships in everyday life. The time span is the transitional progression over time, with critical points and events, such as the establishment of successful strategies and life patterns to comprehend the transition.

Meleis et al. (2000) differentiate between personal, societal and community facilitators and/or inhibitors that might influence the personal transition both negatively and positively, i.e. into a healthy or unhealthy transition. Personal knowledge, interpretation and meaning influence how the person incorporates changes and transition. Cultural beliefs and normative attitudes, as well as socioeconomic status, influence the process of change and transition (Meleis et al., 2000).

The societal facilitators or inhibitors involve significant others (e.g. family members, friends), social networks and healthcare providers, if the transition is optimal and facilitators are present. The person should reply with patterns of response, such as feeling connected, interacting, feeling located and situated in the new situation, as well as developing confidence and coping. For the person completing a healthy, positive transition, the outcome and end-point should be a feeling of mastery; i.e. developing skills to manage the new life situation, as well as accepting and integrating the change and, if necessary, reformulating a new identity accordingly (Meleis et al., 2000).

Transition theory has been used as a theoretical framework or perspective in a variety of nursing research fields, such as developmental transitions (Meleis, 2016; Rew, Tyler & Hannah, 2012), discharge and relocation (Meleis & Rogers, 2017; Geary & Schumacher, 2012; Robinson, 1999; Neiterman, Wodchis & Bourgeault, 2015), immigration research (Baird, 2012; O´Mahony, Donnelly, Bouchal & Este, 2012), educational transformation (Cordeau, 2012; Sharoff, 2006), health and illness transitions (Long, Briggs, Long & Astin, 2016; Olsson, Karlsson & Ekman, 2006; Drevdahl & Dorcy, 2012; Pridham et al., 2012), organizational transition (Sullivan-Marx, 2017; Betz, Smith, Van Speybroeck, Hernandez & Jacobs, 2016a) or in different unspecific transitional models (Im, 2011; Im, 2014; Betz, O´Kane, Nehring & Lobo, 2016b). However, the illness experiences of older women living with the diagnosis of osteoporosis and VCF through a perspective of a transition are poorly understood. To be able to describe and understand these women's illness trajectory, it is important to look at different influencing factors that are related not only to their illness condition but also to the time continuum of their life.

STATE OF THE ART

03

03

STATE OF THE ART

3.1 Illness and osteoporosis

Suffering an age-related disease, such as osteoporosis, has subsequent illness experience that have been defined as mundane, inconsequential and life changing but also as unpredictable and overwhelming (Wilkins, 2001a). Wilkins (2001b) accentuate that, in order to achieve a true understanding of the complexity of the way women manage life changes in relation to both aging and age-related illness, it is important to reflect on their sense of self; i.e. how they view themselves in the past, present and future (Wilkins, 2001b).

A frail, deceiving and changing body can result in a fear of falling and incurring a future fragility fracture and subsequently becoming dependent on others and losing autonomy following the illness trajectory (Hansen et al., 2014; Reventlow, Hvas & Malterud, 2006; Bianchi et al., 2005).

An insight into living with the diagnosis of osteoporosis is handled differently and is mostly affected by the way the diagnosis process was established and perceived. The way an aged woman values the importance of a positive diagnosis of osteoporosis varies, depending on what she incorporates in the actual diagnosis. Osteoporosis might be confusing and difficult to accept fully, since it is a silent illness trait, without symptoms, but, at the same time, it encompasses the impending threat of symptoms of a fragility fracture (Weston, Norris & Clark, 2011).

According to Nielsen, Huniche, Brixen, Sahota & Masud (2013), information and knowledge might either empower or paralyze, depending on the person's social network, economic situation and his/her resilience and intrinsic capability, and it should therefore be given with this in mind (Nielsen, Huniche, Brixen, Sahota & Masud, 2013).

It is not only the bodily image and understanding of an aging body that changes when the diagnosis is set but also psychological aspects, such as reduced HRQoL and well-being, with reduced social activities and a more depressed state of mind (Guillemin et al., 2013; Bianchi et al., 2005; Roberto & Reynolds, 2001). In a descriptive study, Wilkins (2001b) further elaborated on the different strategies used by women living with osteoporosis to manage their new life situation. They identified three stereotypes; those with confident selves who use acceptance to achieve balance in everyday life and are able to take part in meaningful activities; those with contradictory selves, who use denial to attempt to regain control over their lives and, thirdly, those with disparaging selves, who have poor self-reliance and use resignation before the diagnosis as a way of managing everyday life (Wilkins, 2001b).

3.2 Illness and long-term back pain

The experiences of older women living with long-term back pain are defined as a complex, multifaceted condition, due to both physical deficiencies and emotional, mental and social expenditure (Makris et al., 2014c, 2016; Bunzli, Watkins, Smith, Schütze & O´Sullivan, 2013; Kugelmann, 1999). The emotional distress is characterized by sadness, anger and depression, before being forced to accept and manage physical deficits, alongside the feeling of isolation in both place and space and loneliness due to avoidance or being avoided by family and friends (Marshall et al., 2016; Newton, Southall, Raphael, Ashford & LeMarchand, 2013).

During the last century, studies have emphasized the difficulty these women experience in managing pain, or the threat of pain and handling their everyday lives, as it affects physical, social and psychological aspects. In an early study by Paier (1996), the experience of older women suffering a VCF was described as a condition of constant pain, loss of independence related to the loss of capacity, changes in physical appearance with increased kyphosis as well as a sense of vulnerability (Paier, 1996). Several years later, Berlin Hallrup, Albertsson, Bengtsson Tops, Dahlberg & Grahn (2009), presented an unchanged description of experiences, but with a more prominent feeling of loneliness, due to the strategies developed to manage within the security of their home, and an increasingly depressive state of mind when longing for their lives before suffering a VCF (Berlin Hallrup, Albertsson, Bengtsson Tops, Dahlberg & Grahn, 2009). Alteration of the body with increased kyphosis are prominent within the population of women with osteoporosis and VCF (Roberto & McCann, 2011). Hallberg et al. (2010) added further to this picture by describing the women's experience of losing their self-image, with a changing body and belief in their own ability, with a subsequent reduction in self-esteem (Hallberg et al., 2010). This was closely interrelated with the women's perceived health and therefore adversely affected their HRQoL (Hallberg et al., 2009).

3.3 Illness and health-care

Having the diagnosis established by health-care practitioners and accepting living with osteoporosis have been described by older women as equivocal and multifaceted (Hansen et al., 2014; Beaton et al., 2012). Some women described a sense of being taken seriously by physicians, whereas others described an extended process, during which they were forced to become their own health advocate (Hansen et al., 2014). Losing control over the physical and psychological aspects of their life made these women more vulnerable to external adversity, such as poor management by health-care providers (Hallal, 1991). The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) completed a report to identify and summarize the current evidence relating to the care of osteoporotic patients in Sweden. One part of the report involved examining how persons with osteoporosis perceived their management by health-care providers. The results presented a disturbing description of receiving incomplete, inaccurate or even contradictory information with regard to the diagnosis, pharmacological treatment and recommendations for physical restrictions. They also portrayed a sense of being abandoned, since the physician, considering their symptoms as a normal part of aging, neglected the diagnosis of osteoporosis and its subsequent future fracture risk (SBU, 2017).

Back pain, regardless of cause, is a most troublesome symptom for many people, but many older adults never seek health-care, since the pain might be regarded as a part of the normal aging process. However, it has also been suggested that the development of polypharmacy or addiction to pain medication, as well as fear of surgery, are possible underlying motives for avoiding health-care services (Makris et al., 2015). Appointments with health-care practitioners have been described by people with long-term back pain as being disregarded and the experience of illness being diminished, with ignorant disinterest on the part of health-care providers. Being forced to ensure and to convince health-care providers that the symptom of pain is real and disabling, while maintaining autonomy and dignity, can be a major problem (Werner & Malterud, 2003; Kirby, Broom, Adams, Sibbritt & Refshauge, 2014).

04 RATIONALE

04

RATIONALE

Growing old is something that most of us will be fortunate enough to learn, with benefits such as greater experience and wisdom, with greater self-awareness, self-esteem and knowledge of the world. However, it might also imply disadvantages, with weakened bodily functions, changes in body constitution, cognitive impairment and a greater need for support. We all want to grow old with intact physical ability, maintained stamina and strength. However, most of us know that we will be forced to encounter disability and age-related conditions, which we shall have to endure and take along for the journey.

One common age-related disability is back pain, which is demarcated by its duration, i.e. acute, sub-acute or persistent or long-term back pain. Back pain generates impaired balance, inferior walking ability and an increased risk and fear of falling. One common cause of back pain in old age is VCF caused by osteoporosis, mostly affecting women after menopause, but degenerative disc disorder is another cause. The impact on a person's life and the experience of living with a VCF and long-term back pain is poorly understood.

What we know is that when seeking health-care, older women with osteoporosis and VCF are often unnoticed and looked upon as "lost causes", since little is known about the disease trajectory and little or nothing can be done about their condition or relieve and reduce symptoms. Most recommended interventions involve physical activity, while few studies highlight the importance of nursing and the expressed needs and desire by the women themselves for potential support.

The rationale for this thesis is to give a voice to older women living with osteoporotic VCF and persistent back pain, by describing their life situation from different viewpoints and identifying their resources, motivations and strategies for managing everyday life. There is a need to investigate the impact on HRQoL, the consequences of long-term back pain for physical disabilities and its effect on social interaction and mental health. Narrowing the knowledge gap and increasing our understanding of these women's situation will create prerequisites for health-care systems and society to support them as they progress through transition and find ways forward with pain as a fellow traveler.

05

AIM

5.1 Overall Aim

The overall aim of this thesis was to obtain a comprehensive understanding of older women's experience of living with osteoporotic VCF and back pain.

5.2 Specific Aims

Study I:

The aim of this study was to examine physical function, self-reported activities of daily living (ADL/IADL), health-related quality of life (HRQoL), and sense of coherence (SOC) in 70-year-old women with intense long-term back pain.

Study II:

The aim of this study was to investigate whether a history of clinical VCF but also hip fracture was associated with level of HRQoL in older women compared with women without any VFA verified vertebral or other clinical fracture and to determine whether the association remained over time since the clinical diagnosis of the fracture.

Study III:

The purpose of this systematic review was to identify and summarize the current evidence of person-centered or other structured non-medical/non-surgical interventions supporting older women after an osteoporotic VCF.

Study IV:

The aim of this study was to illuminate the lived experience of women with an osteoporosis-related VCF.

06 METHODS

06

METHODS

6.1 Methodological framework

The focus within nursing lies not only within the illness, disease or disability in itself but also within the persons interpretation, life experience and reaction to the present, threat or influence of illness, disease or disability. For this reason, epistemological stand-point of the research sciences of nursing and healthcare takes its departure with the subjective as the source of knowledge. This in order to better understand the life continuum on which individuals with health-care needs, or significant others to persons with healthcare needs, might be positioned. The aim is also to ensure evidence-based healthcare within clinical contexts, regardless of the level of care that is needed. The subjective aspect might be the person or it might engage the interpretation and understanding at group or at societal level, all depending on the research question at hand. To understand a certain question, a choice must be made based on the standpoint of the knowledge that is being sought rather than methodological stance. Åsberg 2001 argues that the dichotomy between a quantitative and a qualitative research method is a construct of course of action in order to manage data and refers to the different characteristics of the phenomena chosen for the study, i.e. the approach in which the data is collected. Åsberg suggests that we should describe the data as numeric or non-numeric and focus on the research question and its purpose (Åsberg, 2001). Within this thesis, we use both numeric and non-numeric data as well as objective and subjective material within the different studies, depending on the research question and the aspect of knowledge that we set out to understand.

6.2 Design

Table 2. Overview of the different studies.

	Study I	Study II	Study III	Study IV
Design	Quantitative Cross sectional	Quantitative Cross sectional	Systematic Literature Review	Qualitative
Participants	n= 73 versus 373	n= 130+56+376 versus 1164	7 studies	n= 10
Data collection	Questionnaires and physical tests	Radiological exams, questionnaires and physical tests	Literature search and analysis	Interviews
Analysis	Non-parametric statistical analysis	Parametric statistical analysis	SBU-grade and GRADE	Phenomenological hermeneutics

Study I

The design of this study was a cross-sectional method based on data from the Gothenburg H70 Birth Cohort Studies. This prospective population-based study was initiated in 1971 by Professor Alvar Svanborg, with the aim of exploring health and health-related traits affecting older adults living in both special and ordinary housing in Gothenburg, Sweden (Rinder, Roupe, Steen & Svanborg, 1975). The examinations have expanded since the start, and is now comprising psychiatric and physical examinations; structured health interviews and self-reported questionnaires, assessments of activities and functional disability, key informant interviews, examinations by physiotherapist, extensive laboratory examinations and psychometric testing (Steen et al., 1993; Skoog, 2004; Karlsson et al., 2009).

Study II

To further elucidate the level of HRQoL over time in women with VCF a cross-sectional design was used in Study II, relating to selected data from the Sahlgrenska University Hospital Prospective Evaluation of Risk of Bone fractures study (SUPERB). This is a population-based prospective study performed in Gothenburg, Sweden, with the main aim of investigating the potential ability of bone microstructures to predict future hip fractures. Measurements including self-reported questionnaires, DXA with VFA, high-resolution peripheral quantitative computed tomography (HR-pQCT), bodily exposition and physical tests were conducted and have been reported elsewhere (Johansson, Sundh, Nilsson, Mellström & Lorentzon, 2018a; Johansson et al., 2018b).

Study III

The design of this study was a systematic literature review in accordance with the structure of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement. The statement was developed in 2005 by a multidisciplinary group and consists of a 27-item checklist and a four-phase flow diagram. The items address all the sections of title, abstract, introduction, method, results, discussion and funding and the order in which the various assessments should be created in order to produce a detailed report. It was initiated to improve the reporting of systematic literature reviews and meta-analysis through increased transparency to ensure the credibility and reliability of the findings that are presented (Liberati et al., 2009; Moher, Liberati, Tetzlaff, Altman & Prisma Group, 2009, 2010; Moher et al., 2015). The PICO template was also used; i.e. population, intervention, control and outcome to define the clinical question of the review and give structure to the search (Richardson, Wilson, Nishikawa & Hayward, 1995; Schlosser, Koul & Costello, 2007).

Study IV

In this study, we set out to describe the phenomena of the lived experience in women living with osteoporosis and VCF. A phenomenological hermeneutic method was therefor used, developed by Lindseth and Norberg (2004), inspired by Paul Ricoeur's philosophy of interpretation (Ricoeur, 1976). The method strives to gain an insight into the lived experience in people's lifeworld, describing rather than explaining (Lindseth & Norberg, 2004). As opposed to the phenomenological method that strives to remain as objective as possible, hermeneutics depends on interpretation which can be contextual with historical roots and inflected by our preconceptions (Quinn Patton, 2002; Dahlberg, 1997). According to Norberg & Lindseth (2004), phenomenology and hermeneutics supplement each other through the hermeneutic way of interpreting text and the phenomenological way of understanding the phenomena of expressed lived experience. Therefore, to be able to acquire a possible understanding of the interpreted meaning of what is described, there is a need for both hermeneutics and phenomenology (Lindseth & Norberg, 2004). Through three dialectic levels of the analysis process, the naïve understanding might be seen as an interpretive step, in the light of and dialect movement with, the thematic structural analysis creates a comprehensive understanding to detect and visualize different perceptions of reality and formulate possibilities (Fagerberg & Norberg, 2009; Lindseth & Norberg, 2004). This research method has been used in numerous studies describing the lived experience of older women within different contexts and conditions (Edvardsson, Sandman & Rasmussen, 2003; Hansen et al., 2014; Allan & Dixon, 2009; Sawin, 2012; Fagerberg & Engström, 2012; Lyyra & Heikkinen, 2006; Sundin, Jansson & Norberg, 2002; Strandberg, Norberg & Jansson, 2001).

6.3 Settings and participants

Study I

The sample was systematically obtained from the Swedish Population Register, where 1,839 men and women were identified as being eligible for participation based on birthdays (persons born in 1944 on days ending with 1, 4, 7 or 9). Of those, 451 individuals declined participation and an additional 185 respondents were excluded due to relocation from Gothenburg (n=34), inability to communicate in Swedish (n=53), unable to be traced (n=68) and 30 individuals had deceased. The final cohort comprised 1,203 participants, 559 men and 644 women, with a response rate of 72.3%.

After excluding those with a diagnosis of dementia, the female segment of the cohort eligible for the current study comprised 628 women. To be able to detect differences between women with or without intense long-term back pain, two groups were identified using the following questions.

- Do you have back pain?
- Do you experience back pain daily or weekly?
- Do you experience back pain that requires analgesic treatment?
- Do you assess your back pain as intensive or invalidating?

The reference group (n=373) comprised women giving a negative answer to all the questions, while the target group (n=73) reported back pain, daily or weekly, with prolonged and intense duration. Thus 182 women gave an affirmative answer relating to back pain but those with pain that was neither long-term nor intense in character were excluded.

Study II

Women in the SUPERB study were obtained from the Swedish national population register based on age between 75 and 80 years. A manual screening of eligible women ensured that they did not reside in special housing and that they were within the right age range, resulting in a total of 6,832 women. They were initially contacted by letter, followed by telephone contact. The inclusion criteria were that the women were able to walk with or without walking aids, communicate in Swedish and complete questionnaires as well as provide voluntary consent to participate. A total of 436 women were excluded due to not meeting the inclusion criteria and 3,368 women declined participation, resulting in a final study sample of 3,028 women with a response rate of 47.4%.

Women eligible for the current study were identified by reporting at least one clinical VCF after the age of 50 years (n=130) and a specification of time since the onset of fracture. We also identified women reporting at least one hip fracture after the age of 50 years (n=56) and women with at least one morphometric VCF (n=376). The comparative group were women without any fractures (n=1,164) and they comprised the control group for all analyses.

Study IV

Participants were recruited from an orthopedic primary care unit in Gothenburg over a three month period in 2012. Through a purposeful sampling procedure, participants with a variety of localizations of the VCF, age and physical disability were included in the final sample. The inclusion criteria were set at women, over the age of 65 years, able to communicate verbally in Swedish, one or several radiographically verified VCFs due to osteoporosis with subsequent pain (VAS score ≥5) and physical disability. The exclusion criteria were set at recently incurred VCF (< 1 year), since the aim of the study was to capture the experience of long-term disability as a result of the condition and the transition between states. Seventeen eligible participants were contacted by phone and were given oral information about the study. Two women declined participation due to lack of interest and five women felt they could not manage to undergo an interview due to pain and fatigue. The final sample of 10 women gave their informed consent to participate in the study and an appointment for conducting the interview was scheduled. All the interviews were conducted at a location of the women's choosing and they were thus all held in the women's residence. Before the initiation of the interview, the women were given written information about the study, the voluntary nature of participation and the opportunity to end their involvement during the course of the study. The final sample featured women with a variety of time since onset of fracture, severity of disability and symptom distress subsequent to the fracture. There was also diversity with regard to socioeconomic conditions, from well-situated to underprivileged. The women had a mean age of 80.1 years, ranging from 65 to 91 years, and they lived in a house or apartment, alone or with a spouse or adult child.

6.4 Measurements and instruments

Study I

To describe demographic characteristics and to ensure that there were no differences between the groups, items describing socioeconomic and educational level were included. Also, clinical characteristics such as bodily disposition, previous falls, history of fractures, use of analgesics, and risk factors such as smoking and alcohol habits were included.

Physical function

The level of physical function was measured using six self-reported items as well as physical tests conducted by a physiotherapist. Self-reported items included questions on whether the respondents were able to:

- Bend down and retrieve something from the floor? (yes/no)
- Walk/move indoors (yes/with difficulty/under supervision or not at all)
- Walk/move outdoors? (yes/with difficulty/under supervision or not at all)
- Go for walks? (yes/no) and able to climb stairs? (yes/with difficulty/under supervision or not at all)
- In your spare time, you do things you like (agree/agree somewhat/disagree somewhat/disagree).
- How do you asses your own overall fitness? (Likert scale ranging from very poor to very good)

The objective physical tests included gait speed measured by a 30-meter walk at both normal and maximum pace. Level of balance was assessed by the ability to rise to a height of 50 cm without support and stand on one leg with their eyes open for 30 seconds. Endurance or stamina was calculated on the distance covered during a six-minute walk at normal pace (Pasma et al., 2014).

Self-reported activities of daily living and instrumental activities of daily living

Inability or ability in activities of daily living (ADL) was assessed using the Barthel index of Activities of Daily Living (Collin, Wade, Davies & Horne, 1988; Mahoney, 1965; Wade & Collins, 1988). This index comprises ten domains of function; bowel control, bladder control, grooming, ability to use the toilet, feeding, transfer, mobility, ability to dress, climb stairs and bathing. The summary score range from zero (low function, dependent) to 100 (high function, independent).

Inability or ability in instrumental activities of daily living (IADL), was assessed using the Lawton Instrumental Activities of Daily Living (IADL) Scale (Lawton & Brody, 1969). This instrument provides self-reported information about functional skills necessary to live in the community, and includes eight domains of function; ability to use the telephone, shopping, food preparation, housekeeping, laundry, transportation, responsibility for own medications, and the ability to handle finances. A total score was calculated, ranging from zero (low function, dependent) to eight (high function, independent).

Health-related quality of life

HRQoL was assessed using the Medical Outcome study 36-item Short-Form (SF-36) (Ware et al., 1992; Ware & Sherbourne, 1993; Ware, Snow, Kosinski & Gandek, 1993; Hays, Sherbourne & Mazel, 1995; Steward & Ware, 1992). This general health questionnaire is a generic instrument comprising 36 individual questions, which are summarized using a designated scoring algorithm into eight health concepts; physical function (10 items), physical role (4 items), bodily pain (2 item), general health (5 items), vitality (4 items), social function (2 items), role emotional (3 items) and mental health (5 items). Two component summary scores can be calculated based on the results of the eight health concepts, giving a physical component summary score (PCS) and a mental component summary score (MCS). The health concepts scores range from zero to 100, where zero is equivalent with low HRQoL and higher scores indicate higher level of HRQoL (Salaffi, De Angelis, Stancati, Grassi & Pain, 2005; Ware et al., 1995). The Swedish version was developed by Sullivan et al. in 1995 (Sullivan, Karlsson & Ware, 1995).

Sense of coherence

Sense of coherence is a description of a person's ability to respond to pressure and manage challenging life situations. In the present study this was assessed using the shorter 13-item version of the sense of coherence scale (SOC) (Antonovsky, 1987, 1993; Eriksson & Lindström, 2005). The scale consists of three dimensions; comprehensibility (cognitive, five items), manageability (instrumental/behavioral, four items) and meaningfulness (motivational, four items), rated on a scale from one to seven, calculated to produce a total summary score, ranging from 13 to 91.

Higher scores indicate a stronger sense of coherence and, according to Antonovsky (1987), should SOC be regarded as a global disposition and a single entity and should therefore only be reported at total score level rather than at sub-score level (Antonovsky, 1987).

Study II

In order to safeguard the homogeneity of the different groups at baseline, characteristics such as age, height, weight and physical function (i.e., standing on one leg, grip strength, rising up from a chair) were included. The participants answered a questionnaire including self-reported smoking habits, alcohol consumption, co-morbidities (i.e. rheumatoid arthritis and prior stroke) as well as the use of p.o. glucocorticoids and heredity for hip fracture and fracture history (hip, wrist, spine, shoulder/clavicle, upper arm, rib/sternum, femur, knee, lower leg, foot/toe, hand/finger or other), in addition to HRQoL (SF-12) and physical activity (PASE).

DXA and VFA

DXA provides an estimate of the density of the bone (BMD) and is usually measured in the spinal column, wrist, upper or lower arm, hip, leg or full body. In the present study, the measurements of all the participants were made at the femoral neck, total hip, and lumbar spine. It also provided lateral images of the spine, thereby enabling a VFA of the possible presence of VCF through visual determination in accordance with Genant et al. (1993), a semi-quantitative classification of severity and shape (Genant et al., 1993; Johansson et al., 2018a).

12-Item Short-Form Health Survey (SF-12).

HRQoL was self-reported using the (SF-12) questionnaire, which derives from the wieldy used Short-Form Health Survey (SF-36) developed from the multidisciplinary Medical Outcomes Study (MOS) of patients with long-term/chronic conditions. The SF-12 comprises 12 questions affecting health-related aspects within eight domains; physical function, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health. Based on these eight domains, two component summary scores are calculated, describing the respondents' level of physical HRQoL (PSC) and mental HRQoL (MSC). Each component summary score ranges between zero-100, where higher scores indicate a higher level of HRQoL (Ware Jr, Kosinski & Keller, 1996; Jakobsson, Westergren, Lindskov & Hagell, 2012; Gandek et al., 1998; Cheak-Zamora, Wyrwich & McBride, 2009).

Physical function and activity

Several physical tests were used to establish the level of the participants' physical function, including balance (ability to stand on one leg with eyes open for 30 seconds), grip strength (i.e. strength in both hands using an hydraulic hand dynamometer) and lower extremity muscle strength (i.e. 30 second chair stand without support) (Giorgetti, Harris & Jette, 1998).

Physical activity was assessed using the physical activity scale for the elderly (PASE), developed for individuals over 65 years. This is a validated self-reported questionnaire comprising 12 questions relating to the level of activity the participant assesses they have been doing during the last seven days. A total score is calculated giving an indication of mild, moderate or intense level of current of physical activity (Washburn, McAuley, Katula, Mihalko & Boileau, 1999).

6.5 Data collection

Study I

All psychiatric and somatic measurements were made by research nurses or physicians, either at the study center in Mölndal or, if so desired, in the participants´ homes. The data insertion was continuous and, in order to reduce the risk of error rate, double insertion was used with continuous monitoring of the process. The examinations were made in 2014 to 2015, where 1,190 participants completed the physical examinations and 1,189 completed the psychiatric examinations.

Study II

The physical tests, as well as the DXA and VFA examinations were conducted at the Osteoporosis Clinic, Department of Geriatrics, Sahlgrenska University Hospital, in Mölndal, Sweden. The questionnaires were sent to the participants' residents and were completed at home, to be brought to the clinic at the time of measurements, which were all made on the same visit. The questionnaire was screened during the visit at the clinic to detect any missing items. If any questions had still not been answered the women were contacted by phone to enable them to give a complementary answer. The data were inserted using a software program in order to prevent the risk of double registration. The examinations and data collection were conducted from March 2013 through May 2016.

Study III

Search method

The literature searches in the PubMed database and Cumulative Index for Nursing and Allied Health Literature (CINAHL) database were based on the search terms; "osteoporosis" OR "osteoporotic" AND "vertebral" AND "fracture" OR "fractures". In the PubMed database, the terms were combined as MeSH terms or terms in Title/Abstract and as text words in CINAHL. The search was made without limitations in terms of publication date or status, length of follow-up or study design in order to minimize the risk of overseeing or losing eligible studies that might contribute to the result of the review; however, a restriction to the English language was applied. The search took place between March through June 2015. To make it possible to include an equitable and comprehensive set of eligible studies, a by-hand review of the included studies references was also conducted.

Study selection

All studies comparing interventions with established treatment, both randomized trials and other study designs, e.g. observational and cross-sectional studies were included, while reviews, recommendations, epidemiological studies, case reports, letters, commentaries and abstracts were excluded. The inclusion criteria were studies published in English relating to a female population, aged ≥65 years, living with one or more VCF in the lumbar or thoracic spine due to osteoporosis. The primary outcomes were outlined as pain, HRQoL, fear of falling, and social and physical isolation, whereas physical activity was set as a secondary outcome.

Table 3. Population, intervention, control and outcome (PICO).

P	Women, ≥ 65 years, osteoporosis, one or several vertebral fractures
I^1	Interventions based on person-centered approach
I^2	Other supportive interventions
C	Conventional treatment
O	*Primary:* pain, quality of life, fear of falling, social and physical isolation *Secondary:* physical function

Since the search strategy was conducted in order to obtain the most comprehensive set of studies possible, the initial demarcation of the results was made in stages; initially removing the duplicates and then gradually narrowing the number of studies. Studies that were excluded were done so based on study population (men irrespective of age or women ≤65 years), study design or aim of the study, since the present study concentrated on person-centered or other supportive interventions. The titles and abstracts of all publications were assessed and evaluated by three authors independently, and were then compared with regard to data and assessments to ensure comprehensiveness and consistency. Four categories were formulated with regard to suitability of the individual studies to be included in the present study; (1) eligible studies that were considered relevant according to the inclusion/exclusion criteria (PICO); (2) possibly eligible studies that needed to be read in full text to conclude whether they might be considered relevant to the present study aim; (3) not feasible for the present study since it was not possible to determine its relevance with regard to the adopted inclusion/exclusion criteria (PICO), although the references were appraised to determine any overlooked publications, and (4) ineligible for this review with regard to the inclusion/exclusion criteria (PICO). Conflicting conclusions were resolved by conferring until consensus was reached.

Data extraction

The same authors independently re-read the remaining studies (categories 1 and 2) in full text and reached a joint conclusion on the studies that were going to be included in the present study.

From a nursing science perspective, the experiences of improvement in health and well-being were defined with regard to the outcomes i.e. maintain physical activity, experiences of pain and fear of falling, as well as HRQoL and social and physical isolation. This was done, not only to maintain a common ground and understanding of the experience, but also to avoid the possibility of producing a data-driven analysis.

For the purpose of the present study, the definitions were articulated as follows. The significantly high levels of pain, were measured by using validated instruments such as the von Korff pain intensity score or VAS, or described in narrations as prolonged and unforgettable, affecting every aspect of daily life (Hallberg et al., 2010; Suzuki et al., 2008). HRQoL was based on individual views of their life situation, within a cultural context, from the aspects of physical health, functional capacity, emotional and social well-being and the values of personal goals, anticipations, morals and apprehensions (Cella, 1994). Fear of falling, was measured by using validated instruments such as the Falls Efficacy Scale International (FES-I) (Yardley et al., 2005), indicating the persons lack of confidence and fear of performing basic tasks resulting in activity restrictions, changes in exercise behaviors leading to an increased risk of actually falling (Resnick et al., 2014; Hübscher et al., 2010). Social and physical isolation in the sense of being confined to their residence and not being capable of participating in social activities (Klazen et al., 2010). Maintaining physical ability, function and capacity to sustain existing levels of physical function, but taking into account normal age related decline and with possible presence of comorbidity (Kammerlander et al., 2014; Caspersen, Powell & Christenson, 1985).

Research questions guiding the data extraction, assessment of the study relevance but also establishing the point of departure in the analysis process were as follows. What kind of person-centered or other supportive interventions have been tried and investigated in a population of older women with osteoporosis and VCF?; what is the current state of scientific knowledge of person-centered or other supportive interventions for maintaining physical function, decreasing pain and fear of falling and increasing HRQoL in older women living with osteoporotic VCF?; and, finally, what is the knowledge in terms of reducing social and physical isolation among older women suffering from a VCF using person-centered or other supportive interventions?

Study IV

Narration

Narration is a means of describing the past, elucidating the present and envisioning the future. We reveal ourselves to others, obtain structure, process incidents and deduce experiences to acquire an understanding of our actions and values (Scott, Ahlberg, Ekman, Frid & Öhlén, 2004; Ekman & Scott, 2005). Within the personal narration, cultural and social forms become visible from an individual perspective based on experience. Narrations therefore have a therapeutic significance in that the narrator is able to reflect on their own experience and may possibly convey new aspects in order to understand their situation (Quinn Patton, 2002; Scott et al., 2004; Denzin & Lincoln, 2011). The concept of narratology was formulated by the literature researcher Tzvetan Todorov, with the aim of giving literature sciences a more prominent structure and being regarded as a scientific discipline. He described the narrative grammar based on two different motives, the mythological and ideological, and two passages within a narration, one describing the condition and one describing the transition between one condition and another (Scott et al., 2004; Aspelin & Lundberg, 1971).

Interviews

All the interviews were conducted by the first author over an eight-month period in 2012 and 2013, with the main goal of getting the women to narrate their lived experience as freely as possible. Each interview was initiated with an open-end question; can you tell me what it's like to live with a vertebral compression fracture? The individual interviews lasted between 50 and 75 minutes, during which time the interviewer was able to ask exploratory questions which deepened the narration and created an opportunity for the women to reflect on their experience of the way the fracture had affected various aspects of their every-day life (Strandberg et al., 2001; Lindseth & Norberg, 2004). To ensure that the aim of the study remained at the forefront, the interviewer kept the following aspects in mind throughout the interview; experience of sense of self and bodily changes, illness experience, coping strategies to manage subsequent symptoms after the fracture and support the women have, or wish to have, in their everyday life. Throughout the interview, field notes were taken to describe details relating to context with regard to atmosphere, setting, gestures and body language and if other family members were present. The field notes formed a supplement in the analysis process with regard to context and emotions but they were not included in the structural analysis (Lindseth & Norberg, 2004). All the interviews were recorded and transcribed verbatim by the interviewer to avoid any discrepancies between the oral and written narrations (Strandberg et al., 2001).

6.6 Method of analysis

Study I

In study I, descriptive statistics were used to illustrate the deposition of each of the groups. For continuous variables, the mean, standard deviation and median was calculated and the categorical variables were presented as frequencies and percentages. To identify potential differences between the groups, we used the non-parametric Mann-Whitney U-test for continuous data and Fisher's exact test for dichotomous values.

Missing values were managed using the half-scale method in the data from the SF-36 (Sullivan, Karlsson & Taft, 2002), whereas, in SOC and ADL/IADL, the amount of data missing was considered sufficiently low in number and would thus not affect the outcome. For the single self-reported questions, the number of participants was reported as the total number of respondents in each group, but with variations with regard to missing values between the individual items. IBM SPSS Statistics Data Editor (Version 24) was used and a p-value of <0.05 (two-tailed) was considered statistically significant.

Study II

Women with clinical VCF were compared with women without fractures. A subgroup analysis was conducted on women with clinical hip fractures and women with VFA verified VCF, compared with women without any fractures. Women that had both a clinical VCF and a clinical hip fracture (n=6) were excluded from the analysis. Differences between the groups were tested with an independent samples t-test for the continuous variables and chi-square for the dichotomous variables. In order to determine a potential association between HRQoL and time since clinical fracture compared with women without any fractures, the women with clinical fractures were subdivided into tertiles in terms of years since fracture onset. ANOVA was used to determine whether the mean of the three groups and the control group differed, followed by the post-hoc test (least significant difference) to determine differences between all the groups in comparison to one another. Finally, a linear regression analysis was conducted to investigate whether a VCF was associated with lower PCS independently of other covariates (age, height, weight, current smoking, MCS, prior stroke, and grip strength) and for how many years this association persisted. The statistical analysis was performed using SPSS (version 24, IBM) and a p-value of <0.05 (two-tailed) was considered significant.

Study III

In the analysis of the relevant and selected studies, the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) checklist was used. It assesses the quality of the study, i.e. if there is a possibility of systematic errors and/or conflicts of interest, as a result of risk of selection, performance, assessment, attrition and reporting bias. This evaluation forms the basis on which the subsequent classification and the overall assessment of strength of scientific evidence are made, using Grading of Recommendations Assessment, Development and Evaluation (GRADE). This includes the transferability/relevance of the studies, the precision of the data, the risk of publication bias, consistency/conformity, effect sizes, the precision of the data and risk of publication bias but also the likelihood that the effect will be underestimated. The strength of scientific evidence is stated on four levels; high (++++), moderate (+++o), low (++oo), and very low (+ooo), indicating the effect of results at synthesis level (Schünemann et al., 2008; Guyett et al., 2011a, 2011b, 2011c, 2011d, 2011e, 2011f; Balshem et al., 2011).

Study IV

The analysis process in the phenomenological hermeneutics method entails a dialectic movement from the whole text to parts of the text, or, in other words, the relationship between closeness and distance, within the so called hermeneutic circle or spiral. This circle or spiral refers to the movement between the naive reading, understanding and structural text analysis in order to convey a comprehensive understanding (Strandberg et al., 2001; Lindseth & Norberg, 2004).

Initially, to obtain a sense of the overall phenomena of the expressed experience all the interviews were read as openly as possible, i.e. making a naïve reading to detect a unique description of the phenomena behind the words spoken, to obtain a naïve understanding. Lindseth & Norberg (2004) describe this phase as making "a guess about what lived experience means for the participants" (Lindseth & Norberg, 2004). The transcribed interview text then underwent a structural analysis to identify meaningful units, comprising differences and similarities, which capture the phenomena within the text as a whole. A meaningful unit can consist of a sentence, a paragraph or a part of the text, leading to further condensation (Quinn Patton, 2002). These unites are further coded to be able to formulate subthemes and themes or even main themes. The structural analysis validates or invalidates the naive understanding, making it necessary to perform a secondary naïve reading i.e. the hermeneutic circle or spiral (Lindseth & Norberg, 2004). The structural analysis can consequently be seen as developing and deepening the initial interpretation of the text, making a new interpretation in which new expanded and exposed preunderstandings are possible (Ericson-Lidman & Strandberg, 2009; Lindseth & Norberg, 2004). As a last step in the analytic process, a critical reading of and reflection on the interview texts as a whole is performed, with the naïve understanding and themes in mind. In relation to previous research and related literature, the naïve understanding and structural analysis, a comprehensive understanding of possible experiences of the phenomena of living with a VCF is formulated (Lindseth & Norberg, 2004).

6.7 Ethical considerations

All the studies in this thesis were designed and conducted in accordance with the World Medical Association Declaration of Helsinki (1964; 2001). The declaration states that human research should safeguard the security, health, dignity and autonomy of the participant, as well as considering and minimizing possible risks of respondent burden. Informed consent must be obtained from each participant and his/her autonomy must be respected by giving the opportunity to discontinue participation without any reprisal. Anonymity must be ensured in the handling of personal information and both positive and negative results should be published and made public. Research on human subjects should strive to contribute to increased welfare and the development of enhanced and improved prophylactic, diagnostic and therapeutic procedures but also to increase our understanding of the etiology and experience of various conditions (World Medical Association, 1964, 2001).

Research aiming to describe life situations and experiences of an exposed and frail study population, with substantial illness experience, needs to consider several ethical aspects. An invitation to participate in the research should be made in such a way that the respondents don't feel strained to accept the invitation but should instead be given time to consider whether to agree or decline participation. For this reason, the women in the studies were first given written information and then contacted several days/ weeks later by telephone, giving them time to contemplate without being influenced by the researcher.

In the population-based studies (Study I and II), the large number of specific questions with regard to lifestyle factors, private information in terms of function and psychiatric subjects might be perceived as an infringement of personal integrity. This is one reason for why it is important for the respondents to feel confident and secure in the way the data is processed and handled in terms of personal data and anonymity.

The time and place of the interviews in Study IV were decided by the participants in order to reduce the respondent burden.

A substantial time frame needs to be set for each interview in order to allow the participants to tell their entire story without being interrupted. With the knowledge that narrations might give rise to emotions and thoughts that the participants want and need to address, an action plan for the possible need for consultation by another profession was outlined.

It is of upmost importance that the respondents are informed that they can end their participation in the study at any time without needing to state any reason or experience any subsequent consequences. Informed consent was obtained from all participants before inclusion and the collection of data or interview in Studies I, II and IV. They were guaranteed confidentiality by the manner in which the results were handled and presented, thus making it impossible for unauthorized personnel to identify them by name. Questionnaires were handled as medical records with regards to confidentiality and the respondents' personal information and data were registered and converted into a code letter/number which was stored at the study center at the University of Gothenburg.

When performing a systematic literature review and then classifying and recapitulating other researchers´ work, it is important to follow good research ethics and practice in acknowledging the extensive, time-consuming effort behind each individual publication. Every research study has its strengths and limitations and they should be clearly stated based on thorough and comprehensive analysis, validating rather than discrediting, in order to identify and summarize the current evidence relating to the research inquiry in a correct and credible manner.

In agreement with ethical guidelines and principles, approval was obtained from the Regional Ethics Committee in Gothenburg for Study I (dnr: 869-13), Study II (dnr: 929-12) and Study IV (dnr: 862-12). For Study III, no ethical approval was required since the individual studies included in the review had all been approved by ethics committees.

07 RESULTS

07

RESULTS

The results of this thesis are based on four studies; taking its departure on a descriptive level on populations in Gothenburg, Sweden, moving on to research world-wide, to descents to an individual experience. This was done in order to, not only describe the multifaceted effects of osteoporosis, VCF and long-term back pain but also its subsequent consequences in the women's everyday lives.

7.1 Study I

Demographic characteristics

In terms of demographic characteristics, socioeconomic traits such as living set-up (i.e. single or cohabiting) and type of housing (apartment or detached/terraced/semi-detached house) revealed no prominent differences between the groups. The most common trait in both groups was living with a cohabiting partner in an apartment (rental or bought). The appearance of social networks within the close family was similar in the two groups and the majority of the women reported that they had children (87.7% and 90.4% respectively) and grandchildren (78.6% and 79.5% respectively). Educational levels between the two groups were equivalent, without any significant differences between those with more than compulsory education (86.1% and 81.9% respectively). The majority had completed senior high school (42.7% and 47.1% respectively) and/or college/university (42.7% and 36.2% respectively) or specific vocational education (47.3% and 40.0% respectively). Most respondents in both groups stated that they had ceased gainful employment and only 12.5% respectively 18.4% of the respondents had continued employment and the estimation of the households' monthly income was equivalent (29,200 SEK and 34,462 SEK, respectively ($p=0.063$)). When asked about the extent to which the respondents could do things they enjoyed in their leisure time, the women in the target group reported a lower level of self-determined, satisfying leisure activities than the women in the reference group (85.3% and 96.7%, respectively ($p=0.001$)).

Clinical characteristics

In terms of bodily constitution, the respondents were comparable in height, but there was a difference in weight between the two groups, both in kilograms (68.7 kg and 76.1 kg, respectively ($p<0.001$)) and in body-mass index (25.4 kg/m2 and 28.2 kg/m2, respectively ($p<0.001$)). There were no differences between groups with regard to whether they had fallen during the past year and the majority of the women denied having fallen at all (77.7% and 71.2%

respectively). However, among those women who admitted falling, a greater proportion in the target group acknowledged that they had fallen three or more times during the last year (12.3% and 3.5%, respectively (p=0.006)). With regard to the use of mobility or walking aids, both groups reported that they managed without instrumental support, but those who did use mobility aids (13.4% and 11.3% respectively) mainly used a cane/crutch (5.3% and 9.8% respectively) or walker (2.5% and 7.8% respectively), mainly while spending time outside. In terms of fracture prevalence, most commonly referred to as fragility fractures of the hip/femoral, wrist/forearm or humerus, there were no differences between the two groups. The small percentage of respondents who specified that they had or have had a VCF was relatively evenly distributed between the groups (1.4% and 1.1% respectively).

The target group used more analgesics compared with the reference group (16.2% and 66.7%, respectively (p<0.001)) in terms of one to two prescriptions/day. With regards to smoking habits, the target group reported higher numbers of lifetime smokers than in the reference group (67.1% and 58.9% respectively). Between the two groups, there was also a difference in terms of how frequently they consumed alcohol, where women without pain had a tendency to drink more often than women with intense and prolonged back pain (44.1% and 30.3% respectively, (p=0.034)).

Physical function

Physical function was divided into two sections; one containing self-report items and one consisting of objective functional tests.

In terms of self-rated ability to move indoors and outdoors, the groups were comparable, with the experience that their mobility was managed to a great extent without assistance or oversight (indoors: 97.2% and 97.8% respectively; outdoor: 94.4% and 96.7% respectively). In addition to unrestrained movement indoors and outdoors within their immediate surroundings, the women in both groups stated that they went out for a walks without any support to a great extent (91.5% and 96.5% respectively) and were able to bend down and retrieve items that had been dropped on the floor (98.6% and 96.5% respectively). However, the ability to climb stairs differed between the groups where the target group described more difficulties or were not able to claim stairs at all (12.7% and 3% respectively, (p=0.001)). When the respondents were asked to assess their own fitness, significant differences between the two groups´ estimates were found, where the women of the target group regarded their health condition as being poorer than that of the women in the reference group, who rated their condition as generally good (87.3% and 96.7% respectively, (p=0.001)).

When measurements of physical function and endurance were conducted using physical tests, significant differences were found between the two groups in all aspects. With regard to gait speed over 30 meters at normal pace, the target group had a mean time that was approximately 1.5 seconds slower (25.5 sec and 23.4 sec respectively, (p<0.001)). When the respondents were asked to increase the pace and walk as fast as they could, the target group showed a mean time of 19.3, sec whereas the reference group had a mean time of 17.0 sec (p<0.001). This could also be seen in the results when measuring the distance covered in six minutes of walking time indoors, where the reference group covered a 77.7 m longer average distance than the target group (451.9 m and 529.6 m respectively, (p<0.001)). Balance was assessed using rising on to a 50 cm height without support, where 21.9% of the target group and 35.9% of the reference group were successful (p=0.021), Standing on one leg was also used to assess balance and the results were calculated on the best of three attempts and showed a 3.6 sec difference between the two groups, indicating inferior balance in the target group compared with the reference group (22.9 sec and 26.5 sec respectively, (p<0.001)).

Activities of daily living and instrumental activities of daily living

The Barthel Index (ADL) showed that the respondents in both the target and reference groups were mainly independent of assistance and that only a minority of the respondents were defined as dependent (97.7 and 97.6 respectively (p=0.095)). The Lawton IADL scale showed high scores without any difference between the two groups, indicating that both groups were independent of assistance to a great extent, managing their everyday life self-sufficiently (7.8 and 7.9 respectively (p=0.118)).

Health-related quality of life

The results from the SF-36 form revealed significant (p<0.001) differences with regard to HRQoL between the two groups within all eight sub-domains (Table 4). The most prominent difference was seen within the domain of bodily pain (mean diff; 43), which could be perceived as apparent, since this was the main differentiating factor between the two groups. There were also significant differences between the target group and reference groups in terms of the domain of physical function (mean diff; 25.9); role physical (mean diff; 39); and role emotional (mean diff; 29.3). The domains in which the groups were the most similar were social function (mean diff; 17.7) and mental health (mean diff; 10), but there was still a significant difference.

Table 4. HRQoL specified in mean (SD).

	Target group n=73	**Reference group n=373**
Physical function	58.7 (24.8)	84.6 (17.5)***
Physical role	47.4 (42.4)	86.4 (29.4)***
Bodily pain	36.1 (15.1)	79.1 (22.9)***
General health	52.2 (21.9)	76.4 (17.5)***
Vitality	51.2 (21.1)	75.7 (17)***
Social Function	74.3 (26.7)	92.4 (16.3)***
Emotional role	63.2 (43.5)	92.5 (22)***
Mental health	73.1 (17.8)	83.1 (16)***

Mann-Whitney U-test was used to detect differences between groups in terms of HRQoL. *** p<0.001

Sense of coherence

Results from the SOC-13 form and level of sense of coherence in terms of comprehensibility, manageability and meaningfulness showed no differences between the target and reference group (60.5 and 61.3 respectively, (p=0,462)).

7.2 Study II

Participants

In the Sahlgrenska University hospital Prospective Evaluation of Risk of Bone fractures population-based study (SUPERB), a total of 3,028 women completed a questionnaire and physical tests. In this cohort, 130 women reported one or more clinical VCF after they were 50 years of age and they also stated the time since the most recent fracture, ranging from 0.1 to 30.5 years. Another 56 women reported one or more hip fractures after they were 50 years of age and the time since their most recent fracture ranged from 0.8 to 29.3. The control group without any self-reported fractures (i.e. hip, wrist, spine, shoulder/clavicle, upper arm, ribs/sternum, femur, knee, lower leg, foot/toe, hand/finger or other) or radiographically verified VCF comprised 1,164 women.

Clinical vertebral compression fracture

The women with clinical VCF were divided into tertiles, in order to be able to compare them with controls, based on self-reported time since their most recent VCF (median (interquartile range)): T1= 1.84 (1.21-3.05), T2= 7.86 (5.18-9.98) and T3=18.9 (18.8-23.9. Women with clinical VCF within the two first tertiles were shorter (p=0.04) and had a higher prevalence of stroke compared with the control group (p=0.04). Within all tertiles, the women reported an inferior current physical activity level compared with controls (p=0.01), but there were no significant differences in terms of physical performance (balance, grip strength and muscle strength).

In a linear regression model, adjusting for confounders (i.e. age, height, weight, current smoking, MCS, stroke, and grip strength), an association was found between time since most recent VCF and decreased level of physical HRQoL, persisting for up to 18.9 years post-fracture (p=<0.001). However, there was no association with decreased mental HRQoL (p=0.74). In a sub-group analysis, when using reported time since the most recent fracture as a continuous variable rather than a dichotomous variable, there was a significant improvement (p=0.002) in the level of physical HRQoL, but it was still below the scores reported in the control group.

Clinical hip fracture

Women with clinical hip fractures were similarly divided into tertiles based on their self-reported time since their most recent hip fracture (median (interquartile range)): T1= 2.11 (1.08-2.49), T2= 5.10 (4.42-6.39) and T3= 14.6 (10.8-19.8). The number of women with clinical hip fractures within tertile two had a higher body weight (p=0.04) and smoked to a greater extent than the control group (p=0.04). There were no divergences between women with clinical hip fractures and the control group in terms of physical function or level of physical activity. However, the women with clinical hip fractures reported an inferior level of physical HRQoL within the first tertile (p=0.04). There was also a numerical difference in persisting decrease within the physical HRQoL up to 15.7 years, but then again the small sample size in each tertile (T1: n=20; T2: n=18 and T3: n=18) might explain the uncertainty and lack of significant difference.

Morphometric vertebral compression fractures

Of the total cohort, 2,460 women were examined with DXA and VFA and with a semi-quantitative technique for determining the number and severity of verified VCF. As an integer group, the women with morphometric, or radiologically verified, VCF were older (p=0.01) and had a shorter stature (p=0.01) than the women in the control group. They also reported an inferior balance (one-leg standing test) (p=0.01) and lower physical HRQoL (p=0.04), which is in agreement with previous research of the cohort. Of the total 376 women had incurred one VCF (n=273) and 103 of the women had two or more fractures Moreover, to be able to differentiate between the severity of the fractures, the women were divided into mild (n=177), moderate (n=151) and severe fractures (n=48).Through this division, we were able to show that the inferior physical HRQoL persisted, based on both the number of fractures (p=0.003) and the severity of the fracture (p=0.03). A higher prevalence of stroke was associated with the number of fractures (p=0.01) while poorer grip strength was associated with the severity of the fracture (p=0.02).

7.3 Study III

In trying to understand the supportive interventions, other than those of a surgical or medical nature, that have been implemented and attempted for the women with osteoporosis and VCF we turned to the research community and conducted a systematic literature review. From approximately 8800 screened studies, only the small number of seven studies met the criteria and were included in the review with a subsequent GRADE analysis. The final sample of studies had populations comprising women, aged over 65 years with osteoporosis and one or more radiographically verified VCF. Five of the studies evaluated interventions consisting of various physical exercise programs whereas one study evaluated electric stimulation and one an educational program on outcomes of physical mobility, level of pain, social and physical isolation, and HRQoL, fear of falling and psychological symptoms.

Physical mobility

By using physical tests, such as maximum walking speed, and Time Up and Go (TUG), several studies showed that the women improved their physical mobility following the implementation of different physical exercise interventions. Balance was assessed using the Functional Reach (FR) test or force-plate measurement and three of the four studies were able to show significant differences between the women and the control group during follow-up (3, 6 and 12 months). Only one study assessed the women's strength using a standard protocol (B-200 Isostation) and was able to report a significant improvement at both six and 12 months. In terms of quality of evidence, it was shown that physical exercise probably improves the physical mobility for women with osteoporosis and VCF and the result was rated as moderate (GRADE +++0).

Pain

Level of pain was evaluated in three of the studies, assessing the effect after physical exercise, a coping and education program or electric stimulation. To detect a decrease in the women's level of pain, the studies used various scales and questionnaires such as the 11-point box scale, Functional Status Index (FSI) or a standard VAS scale and the Backhill questionnaire. The study evaluating exercise were able to report a decrease in the women's level of pain but also a reduction in the use of analgesics. The coping and educational program showed no reduction in pain with activity among the women with osteoporosis and a VCF, but a deterioration in the control group. One study evaluated the effects of two different electric stimulation techniques compared with placebo and it showed an improvement in both groups at follow-up.

All three studies had some study limitations and uncertainty with regards to precision which generated quality of evidence for physical exercises as low and only slightly improved pain (GRADE ++00), whereas electric stimulation probably improves pain in women with osteoporosis and VCF with moderate quality (GRADE +++0).

Social and physical isolation

None of the included studies reported on the effects on experience of social and physical isolation in women with osteoporosis and VCF.

Health-related quality of life

Effects on enhanced HRQoL were the most commonly evaluated outcome and were reported in four of the studies, three randomized trials and one observational study. The potential improvement in HRQoL for the women with osteoporosis and VCF was assessed and evaluated using diagnosis-specific questionnaires, such as the Quality of Life Questionnaire issued by the European Foundation of Osteoporosis (QUALEFFO-41) or the Osteoporosis Quality of Life Questionnaire (OQLQ) or more generic HRQoL instruments such as the General Health Questionnaire (GHQ-20), the Sickness Impact Profile (SIP) or the Medical Outcome Survey short-form (SF-36).

The three randomized trials, with a total of 215 participants, reported effects of exercise or coping classes on experience of HRQoL and found that the women improved at both three and 12-month follow-ups. The observational study that estimated the effect of an educational program was not able to detect any improvement in the women's HRQoL at follow-up after eight weeks. In terms of quality of evidence the three randomized trials were graded as being of moderate quality and exercises and/or coping classes were considered probably to improve HRQoL (GRADE +++0), whereas the observational study was of very low quality (GRADE +000) making it uncertain whether educational support improved the women's level of HRQoL.

Fear of falling

One randomized trial evaluated the effect of an intervention comprising coping techniques, body awareness and ergonomic advice in everyday situations in order to reduce the women's experience of fear of falling. They used the Falls Efficacy Scale International (FES-I) and found a significant reduction within the intervention group but also a difference between the women in the groups at both three and 12 months, as well as an increase within the control-group. The finding in this study, along with its moderate quality of evidence (GRADE +++0), implies that exercise and education probably reduce fear of falling.

Psychological symptoms

The one study assessing the effects of exercise and coping classes, addressing stress reduction, relaxation and lifestyle modifications, on the women's psychological symptoms used the Global Severity Index (GSI) to illustrate potential differences. A significant difference at six and 12 months indicated that exercise and coping classes probably reduce psychological symptoms with a moderate quality of evidence (GRADE +++0).

Syntheses of results

The seven studies included in this review had some limitations and were mainly assessed as being of moderate quality according to GRADE. They all gave a clear description in terms of allocation and, if relevant, the randomization process, with follow-ups ranging from eight weeks to 12 months, with well-defined outcomes and clear inclusion and exclusion criteria. However, all the studies struggled with some selection bias, in that only individuals with the strength to participate were included, precision with only narrow cohorts and concerns in terms of confounders. Due to the diversity of the studies and interventional design of the studies, as well as methods of assessing and evaluating effects on outcomes, the analysis of this review remained at a narrative assessment and qualitative synthesis level rather than a meta-analysis level.

7.4 Study IV

From an individual point of view, we were able to show that the experience of living with osteoporosis and VCF was demarcated as being thrown into a life situation of turmoil and chaos without any prospects of transition into stability and security in their everyday life, regardless of the time that had passed since initial onset.

Fear and concerns were prominent features in the women's experience of everyday life. Fear of present pain, or the forthcoming onset of pain, made the women cautious, restricted and confined through fear of falling and incurring additional fractures, which altered their sense of self and their position in the world through subsequent loss of confidence.

The fear and concerns made them withdraw from previously appreciated social arenas, resulting in isolation, loneliness and boredom. The body was regarded as frail and fragile, believing that the ability to perform normal tasks was decreasing as time passed.

There were prominent concerns about facing an uncertain future with regard to support from tiring loved ones, forcing the women to become more dependent on support from municipal representatives or even being forced to leave their homes for a more institutionalized environment.

"... It's a scary thought of being dependent on or a burden to someone. I think most people in my generation want to be independent. And I have always been like that. So it is ... I don't want to think about it so I take each day as it comes."(Interview 7)

Pain was perceived as a constant companion, not only decreasing and limiting the women's physical ability but also leaving them longing for what once was. Changes to their physical appearance in terms of loss of height and a pronounced stooped posture with a protruding stomach were regarded as bodily decay beyond their control with fatigue and inability to straighten their back with increased stiffness as a result.

The future for these women was a matter of insecurity and inability to look forward, both due to the pain as a constant traveler but also in some cases with regard to advanced age. Living day by day and taking the level of daily illness-experience and intensity of pain as the determinant of choices of activities. Hopelessness and loss of inspiration made life dull and grey and got in the way of opportunities to plan for dreams for the future

"And what I think about is if I'm going to live like this with this pain for the rest of my life? The idea is very frightening, to go on like this all my life, I don´t know if I'm up for that!" (Interview number 8)

The contact with healthcare providers was seen as disappointing, unsatisfactory, frustrating and inadequate. They all felt they were being belittled, marginalized and not taken seriously as they were woman of advanced age. They were treated as untrustworthy when expressing diffuse and unmeasurable symptoms, which healthcare providers mainly regarded as a part of the normal aging process. In their efforts to receive support in handling their new life situation with pain and discomfort, they encountered attitudes of uninterested indifference, creating a sense of guilt and no longer being a significant part of society, not worth investing in and, in a sense, a burden and liability on the healthcare system.

"But it is how you perceive it, that when you become older you don't count as much any longer; you can't get the same care you got when everything was well. The older you get, the less you count, you are not nourishing, you are only consuming." (Interview number 10)

However, when facing the loss of freedom with feelings of confinement, the desire to find new ways to maintain their independence and strive forward increased. The women described great satisfaction in managing small and large every-day life chores, showing both ingenuity and vigor to maintain autonomy and independence. Through their narrations, the women wanted to make sure that they were perceived as capable, susceptible individuals, but they emphasized that they were simply abandoned in turmoil and an unstable situation with pain as a constant traveler.

08

DISCUSSION

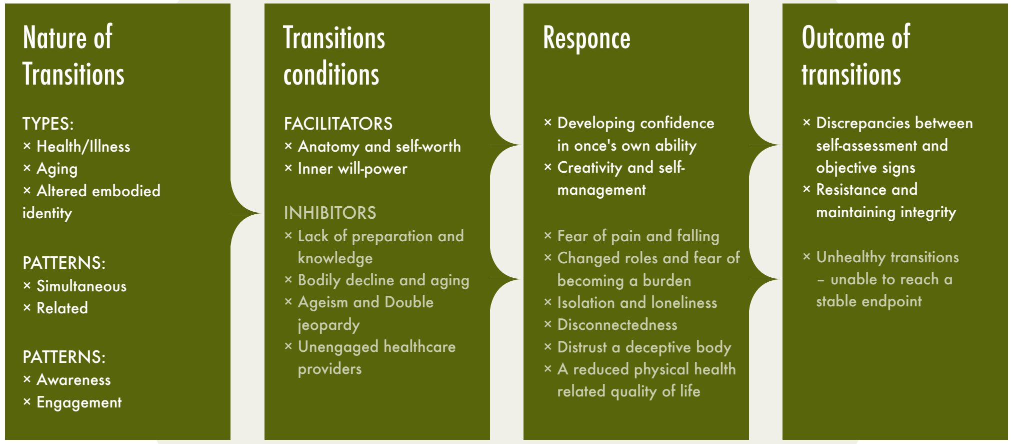


Fig. 7 Adjusted model of the Transition Theory by Meleis et al., 2000
(By Guðni Ólafsson)

08

DISCUSSION

The women who have been given a voice in this thesis paint a dark picture of their lives with fears and concerns, about both constant pain and breakthrough pain, as well as performing aggravating voluntary or involuntary movements generating strict restraints on everyday life. They tell a tale of turmoil, poor HRQoL, instability and mistrust towards their own body but also disappointment and a low sense of worth in the eyes of the health-care system and society. As previously described significant events in a person's life, such as incurring a VCF and experiencing long-term back pain, initiate a transition, a passage between different stable states or positions on the life continuum. There is personal characteristics and external factors that determine whether the transition will be healthy, i.e. reaching a new and stable position, or interrupted, i.e. negative in nature. Hence, to illuminate and try to understand these women's everyday life as it progresses with a VCF and long-term back pain the discussion of the main findings in this thesis will be based on selected parts of the transition theory (Meleis et al., 2000).

8.1 Nature of transitions

A transition is never an isolated process, but multiple transitions happen simultaneously and are related so that they amplify or mitigate one another. The transition the women enter when they incur a VCF and long-term back pain can be reflected upon as a health/illness transition, but there are parallel transitions that become evident simultaneously; the inevitable developmental process of becoming older and a situational transition involving changes in social positions when they are being perceived as dissimilar from before, because of the illness (Meleis et al., 2000).

There are some essential properties for a healthy transition. One is awareness of the illness situation, both in the presence and from a future perspective. However, in order to become aware of the transition the women required detailed and sufficient information relating to their condition, the illness trajectory of the condition and what was expected of them to develop self-care for potential recovery. Another central property of a transition process is movement over time. This implies a journey from their initial well-known life situation, through a state of instability and insecurity, into a new state of stability with acceptance and assimilation of the new life-situation, i.e. reaching an end-point (Meleis et al., 2000).

8.2 Transition conditions

Multiple features affect the trajectory and outcome of a transition. There are both personal and external facilitators and inhibitors that will enhance or reduce the possibility of a healthy transition. Setting the course for the nature of the transition is the meaning that the women impose on the transition, but this can also be reinforced by their cultural beliefs and attitudes (Meleis et al., 2000).

8.2.1 FACILITATORS

Autonomy and self-worth

A salient personal facilitator that the women describe as important was maintaining their autonomy and self-worth, which has also been reported in previous studies (Hallberg et al., 2010). They did not want help with domestic chores from other people, but they instead fought to maintain their autonomy and being able to manage on their own accord. Women with long-term back pain and the women without back pain reported the same low level of using municipal support and assistance in terms of managing activities of daily living (ADL) or instrumental activities of daily living (IADL). They valued dignity as important for their self-worth, which might be a quandary when encountering multiple impediments, but it might also be a motivator for resistance when facing adversity and illness experience.

8.2.2 INHIBITORS

Lack of preparation and knowledge

Knowledge and preparation can facilitate the transition process. However, since incurring a VCF is an event with a rapid and unexpected onset (Gerdhem, 2013), the women were not able to prepare or obtain knowledge beforehand. The women recount for a lack of information from healthcare providers. Both with regard to their condition, i.e. cause of the injury, but also what health-care providers might be able to do in order to reduce their symptoms and what the women should do and what they should avoid in terms of self-care, which further prevents the sense of becoming knowledgeable (SBU, 2017; Nielsen et al., 2013; Paier, 1996).

Bodily decline and aging

Women are more frequently judged by their appearance, rather than by achievement (Chappell & Havens, 1980). Osteoporosis and VCF contribute significantly to changes in the women's bodies, with a more stooping posture, shorter height and a more protruding stomach, which adds to the appearance of an aging woman (Roberto & McCann, 2011; Paier, 1996; Qvist et al., 2011; Kammerlander et al., 2014; Hallberg et al., 2010; Ross, 1997). The fear of falling and pain made them more cautious in their movements and caused them to withdraw from social arenas, both because of a sense of shame over their appearance but also because the bodily changes have reinforced their experience of aging outside of their control and influenced the women's view of themselves. Moreover, being in doubt of having a future and experiencing reduced physical stamina and HRQoL were interrelated to the process of becoming older, to some extent more so than the illness itself.

Ageism and double jeopardy

Being an older person in the western world is often perceived as something negative since society greatly values and aspires to youth and health. This outlook leaves older women with osteoporosis and VCF in a state of not being taken seriously and not being acknowledged as a person that matters. Moreover, socioeconomic traits and resources play an influential role, since we live in a society where financial resources reflect not only our societal status but also our educational level, level of control and success. It could therefore be suggested that, being an older woman with limited economic resources, possibly a widow, in a single household, leaves them in an exposed and vulnerable state. Researchers have suggested that, through the social construct of gender, women display higher levels of unhappiness and stronger feelings of vulnerability, which produce undesirable health perceptions and have a negative impact on women's resistance to illness (Anson, Paran, Neumann & Chernichovsky, 1993; Beattie, Pachana & Franklin, 2010). Previous studies have also revealed a gender difference in pain-related disability, where women have a four times larger number of disability days (Stubbs et al., 2010) and also experience higher levels of chronic stressors (Maire, Cutchin & Peek, 2011).

The concept of double jeopardy has been used since the early 1970´s to describe the negative cumulative effects of gender, age, race and religion, as well as symptoms of distress, impairments or disability (Palmore & Manton, 1973; Jackson, 1972). These authors postulate that the combined effects of two stigmatized characteristics, such as being a woman and being older, are greater than if the person holds either negative status alone (Chappell & Havens, 1980). Within the aspect of gender and aging, Chappell & Havens argued, as early as

1980, that there are more negative consequences to well-being and health status if you are an older woman than if you are an older man, or a younger person, since older woman are valued as one of society's least socially important members (Chappell & Havens, 1980). However, subsequent research on older women's experience and exposure to increased vulnerability, with poorer health and HRQoL in terms of double jeopardy, is sparse. When taking into account the different aspects of double jeopardy, women with back pain and VCF have many stigmatized characteristics accentuating their disabling condition and increasing their sense of alienation and rejection. One might even consider whether there might be some form of triple jeopardy, in that they are not only women and older but also having a condition that is regarded with indifference and lukewarm interest by healthcare providers, thereby amplifying their ongoing vulnerability.

Unengaged healthcare providers

The women's accounts of meetings with health-care providers when seeking help for their back pain were tinged with an ageist attitude, leaving them feeling belittled, unseen, mistrusted and unimportant. Even though some of them received help, they perceived the interaction as distanced, so that they were bound to become their own health advocate and were forced to convince and persuade health-care providers that their experience of illness and pain actually existed and was factual (Hansen et al., 2014; Werner & Malterud, 2003; Kirby et al., 2014). Research has shown that women need to express a higher level of symptom distress in order to be taken seriously and attract the attention of health-care providers (Falk et al., 2016). A prominent feature of the women's reasons for feeling disappointed with health-care providers was the lack of sufficient, relevant information, conveyed in a sincere and respectful manner. Instead, they were left with contradictory information and were often told that the back pain would pass and self-subside within weeks/months (Suzuki et al., 2008). However, the back pain proved to be persistent and continued for up to at least five years for some of the women after a VCF. Moreover, they were informed that there was nothing that could be done in terms of medical treatment for a fractured vertebra, but that they should be patience, persevering and get rest. This leaves the women in a state of distrust towards the health-care professionals and creates a considerable quandary since the women's level of engagement in their own care and rehabilitation process requires and is dependent on awareness and knowledge.

8.3 Response

Based on the findings in this thesis the women responded with a feeling of being disconnected and alienated from the world and the life they knew, withdrawing from social arenas due to shame over a changed and deceptive body, as well as the dread of becoming a liability on the people around them but also striving to develop confidence in their own ability (Hallberg et al., 2010).

Developing confidence in one´s own ability

Despite adversities and obstacles, the women demonstrate a determination to uphold their ingenuity, vigor, resourcefulness and resilience in maintaining an independent life and not to allow themselves to be overpowered and defeated. They refused to let themselves become dependent, but instead worked to believe in their own personal level of motivation and capacity to manage parts of their disabilities.

Creativity and self-management

The women tried to believe in their own ability and against all the odds, they developed practical skills to manage daily chores. They had therefor constructed and created several clever and inventive ways to make their day work, such as using chairs when doing the dishes, taking walks with frequent stops or using aids such as a drama chart or backpack when shopping. They did this to avoid asking for help and letting their condition become the predominant element of their person and identity. Holding aging at a distance by keeping their independence intact and showing people around them that they are capable and fully functional. This fear might also be reinforced by the changes in roles from being a nourishing provider (mother, caregiver and spouse) to a consumer, in need of help and maintenance.

Fear of pain and falling

Fear of present pain or the threat of pain onset made the women more cautious and insecure when moving. The fear of pain was described as almost worse than the pain in itself, since it did not pass but was constant throughout the day, regardless of the presence of pain or not. They chose which undertakings to prioritize, knowing it would be time consuming but also that they might possibly have to pay the price of back pain afterwards. The prostration and stiffness in the back created a sense of imbalance and unsteadiness, increasing both fear and the risk of falling (Wang et al., 2017; Iglesias, Manca & Torgerson, 2009). This insecurity amplified the fear of involuntary overstrain, subsequently making it easier and more secure to avoid certain activities all together. Tense or tired muscles will cause an aggravation of the pain, which was also a reason for the women to be more cautious in their movement and physical exertions (Guillemin et al., 2013).

Changed roles and fear of becoming a burden

The women recognized an underlying fear of becoming a burden and a liability and that significant others would tire if they became too demanding and required too much support and help. This was described as a motivator for managing on their own, even though it took a great effort, but also for diminishing their symptoms in the eyes of others. Robinson (1999) highlighted the effects in patients with hip fractures of going from an independent person to become a dependent individual with a range of physiologic and psychosocial changes (Robinson, 1999). However, Meleis & Im (2002) argue that research tends to reduce women's health-illness experience to a predominantly physiologic and pathologic condition or event (Meleis & Im, 2002).

Isolation and loneliness

Since a person exists within the world and interacts with others, the women were dependent on action and reaction in order to determine and define their identity (Harré, 1997; Hedman, Hansebo, Ternestedt, Hellström & Norberg, 2013; Skaalvik, Norberg, Normann, Fjelltun & Asplund, 2016; Hedman, Hellström, Ternestedt, Hansebo & Norberg, 2014; Hedman, Hansebo, Ternestedt, Hellström & Norberg, 2016). Voluntary and non-voluntary social withdrawal and isolation, with an amplified sense of loneliness and long days, became distinct features in the women's narratives. Research has shown that women express a higher level of loneliness and live more socially isolated lives than men (Nicolaisen & Thorsen, 2014), which, among these women, might be partially explained by an altered embodied identity but also the illness experience in itself. Some of the women also said that they had become reluctant to participate in social interaction and that the fewer the opportunities for doing so became. The sense that from being a healthy, capable woman and becoming disconnected from the social world amplifies the level of isolation and loneliness which was in turn amplified by the feeling of disconnectedness.

Disconnectedness

The immediate community affects the response to a transition, through both accessibility and infrastructure as well as the municipality´s opportunity to offer and provide support and assistance to allow the women´s ability and potential for independence to be as intact as possible (Meleis et al., 2000). It also requires the women to be able to feel like part of the community and to be able to attend and participate in municipal activities. The women´s recognition of having becoming more isolated and lonely might be voluntary, but it could also be due to a lack of opportunities to attend municipal activities in their immediate surroundings.

Distrust a deceptive body

The women looked upon the fracture and back pain as an unjust and unneeded condition, creating resentment toward their own deceptive body. They did not trust their bodily function and stamina and felt deceived when referring to things they were no longer able to do (Qvist et al., 2011; Hallberg et al., 2010).

A reduced physical health-related quality of life

Even though the women strove to maintain confidence in their own ability, they reported a reduction in physical HRQoL 18.9 years after a VCF, which is in agreement with earlier research showing reduced HRQoL three years (Silverman et al., 2012) to seven years post fracture (Hallberg et al., 2009). This might suggest that the condition is not only a persistent and troublesome state but that it also affects the health experience at a more existential level. It also supports the assumption that women do not achieve the acceptance of their changed life situation that is necessary for a successful transition. A study indicated that 75% of women suffering a hip fracture never revert to the same level of physical function after their fracture (Robinson, 1999). The reduced level of physical HRQoL together with the inferior results of the physical tests, might be partially explained by the fear of pain and falling, but a changed in reliance on their bodily capacity made the women more cautious, doubtful and insecure in their movements, which has also been reported in previous research (Hübscher et al., 2010). The importance of addressing the issue of reduced HRQoL in an aging population has been stressed in earlier research (Imagama et al., 2011) and in those with VCF, it has been shown to be underestimated (Ström et al., 2008; Salaffi et al., 2007; Palacios, Neyro, Fernandez de Cabo, Chaves & Rejas, 2014).

8.4 Outcome of transitions

The end-point of a transition according to the original Transition Theory implies the development of skills or mastery to manage the new situation with disability, accepting and integrating the life changes and reformulating one´s identity accordingly (Meleis et al., 2000). There is a dialectic relationship between facilitators and inhibitors that affects the response to and outcome of the transition. Facilitators, such as valuing autonomy and self-worth, as well as inner willpower, might be amplified by the presence of several inhibitors, such as fear of falling and becoming a burden, back pain and a deceptive body, strengthening the women's sense of not giving up. The "two sides of the same coin" can also be seen in the patterns of response and outcomes. Despite the presence of fear of pain and falling, changed roles and fear of becoming a burden, increased isolation and loneliness, disconnectedness, and an inability to rely on a deceptive body, as well as reduced HRQoL, the women try to preserve their integrity, motivation and capacity for maintaining the life to which they are accustomed.

Discrepancies between self-assessment and objective signs

There is a tradition of dividing the subjective illness experience and objective signs, defining disease, to grasp the multifaceted process of incurring a condition. However, this might bring about inconsistencies between the experienced and the measurable. Women living with long-term back pain reported having inferior mental and physical HRQoL and lower self-assessed overall health. However, when the women were asked directly about their physical ability and their management of domestic chores they regarded them mainly as intact as those women without back pain, suggesting a high level of desire and motivation to make things work without support or help. On the other hand, a discrepancy was found between women with back pain and those without, when objective physical tests were performed. This once again indicates that the subjective experience of physical disability is highly dependent on the women's confidence in their own ability and their refusal to allow the condition to confine or restrict them.

Resistance and maintaining integrity

Being able to move forward and navigate new circumstances, while being situated in a new life context, requires some confidence in the own ability. To be able to cope with everyday life and once again find a stable state, an end-point to the transitions is necessary. To do this, the women need enough resistance and resilience not give up and surrender to the new circumstances. This might be fueled by a longing and desire to uphold integrity and to return to being the person they once were. In a study of people moving to a nursing home the same personal resilience was shown to be crucial to obtaining an insight and being able to develop strategies to cope with the new circumstances, which should be supported by health-care providers (Brandburg, Symes, Mastel-Smith, Hersch & Walsh, 2013).

Unhealthy transition – unable to reach a stable endpoint

Most women with VCF and persistent back pain never reach an end-point of stability and closure. Reduced physical HRQoL 18.9 years after the VCF indicates that these women are forced to continue trying tenaciously and persistently to find ways of inserting physical stability into an unstable life situation. Moreover, the women's accounts of turmoil and fear up to five years post fracture enhances the image of being in a situation of dispensation, acting from one day to another. Robinson (1999) describes the transition for women suffering from a hip fracture, who, in contrast to the women in this thesis, underwent a healthy transition to a new state of stability (Robinson, 1999). This might reinforce the belief that a hip fracture is severe, yet treatable, while a VCF is not. However, Olsson et al. (2006) suggested that individuals with hip fractures neither reach an endpoint defined by Meleis (2000) but that they find stability and acceptance, even though they may not regain their previous physical function (Olsson et al., 2006).

A negative experience in the encounter with healthcare providers with insufficient or even contradictory information prevents a healthy transition, since it is through interaction between caregivers and care recipients that the health/illness transition may be uncovered and clarified to acknowledge behaviors and response patterns. In an interview study with patients suffering from cancer, the authors conclude that the main goal of health-care encounters should not focus on the patient's ability to remain stable, but should instead be characterized by flexibility and responsiveness to new ways through the transition (Drevdahl & Dorcy, 2012).

Lack of integrative identity

Understanding and accepting a new situation requires both knowledge and acceptance of the altered identity and previous roles that are now changed or lost. However, many of the women described longing for what had once been and described their ability, not as older women but as younger vibrant females. They explain that they do not see themselves as older women with back pain, and that they will never fully give in, and give up doing things they enjoyed. Within this statement they expressed hope of improvement, if not recovery, but also hopelessness about not having a future. They proposed an ambivalent, shifting acceptance and an ability to integrate the condition into their life due to both personal and societal characteristics, resulting in a non-existent endpoint of the transition.

09 CONCLUSION

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CONCLUSION

This thesis provides increased knowledge relating to the experience of older women living with VCF and long-term back pain. It provides new insights in terms of the characteristics and extent of the subsequent consequences, as well as the influence on the women's everyday lives.

One main finding was the mentally and physically reduced HRQoL in women with long-term back pain. Women also reported reduced physical HRQoL up to 18.9 years after incurring a VCF.

One of the most captivating findings was the discrepancy between the women's own assessment of their ability and that measured by objective measurements, suggesting resilience and strong will-power.

Interventions employed within this population of women are sparse and mainly comprise physical activity, showing a probable improvement in physical mobility and HRQoL. Nevertheless, many women within the population were left out of the interventions since they had too much back pain and physical restraints to participate.

The individual picture painted by women living with VCF and subsequent intense back pain was twofold. The chaos, insecurity and instability of everyday life created restraints, both mental and physical, and missed opportunities for enjoying life. However, the women also described the impediments as a motivator to continue struggling and not surrender to the pain or their deceptive bodies, thereby reinforcing the initial suggestion of the presence of resilience and strong will-power singlehandedly and, to a large extent without support, to find ways forward.

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METHOLOGICAL CONSIDERATIONS

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METHOLOGICAL CONSIDERATIONS

Qualitative and quantitative, or non-numeric and numeric research complement one another, especially when addressing a multifaceted research question. It should be the research question that is being studied that determines the nature of the data and the way in which it should be analyzed (Polit & Beck, 2016). A qualitative design aims to explore and deepen the understanding of a phenomenon rather than explain and generalize, whereas a quantitative design is hypothesis testing and determines relationships between variables and different measurements (Polit & Hungler, 1999). In this thesis, different designs and data sources were used to create as valid and comprehensive understanding as possible of the women's situation. The following section addresses the methological considerations arising from each study.

In descriptive Study I, there was the issue of a relatively small sample size (n=73), which is more of a limitation when conducting hypothesis-testing studies rather than descriptive ones. Non-parametric statistical analyses were used due to the small sample size and with no assumption of normal distribution within the study groups. The study also included a large number of variables, since the aim of the study was descriptive rather than hypothesis testing.

Study II had a relatively limited sample size (n=130) and, moreover, the group of women with clinical VCF and hip fractures was divided into tertiles. This was done as we wanted to compare the different time ranges with a control group, but it also generates a risk of a type II error, referring to the risk of determining a conclusion that no difference exists when one actually does. (Altman, 1991). HRQoL was measured with the SF-12, a shorter version derived from the SF-36, and it was chosen as it reduced the respondent burden in what was already an extensive set of questions. However, the SF-12 yields a less individually detailed picture of HRQoL, since it should only be reported at component summary score level and not on the eight health domain level, which the SF-36 permits. Cronbach's alpha is a statistical value of the internal consistency of an instrument, ranging from zero to one. For the SF-12, Cronbach's alpha values have been reported in previous research at 0.89 for PCS and 0.86 for MCS, indicating good internal consistency (Cheak-Zamora et al., 2009; Ware et al., 1996; Gandek et al., 1998; Jakobsson et al., 2012; Altman, 1991).

Systematic literature reviews are designed to generate research questions, establish the level of knowledge within a research field and provide a conceptual context. However, they may also be regarded as research on research with a specific question of interest (Polit & Hungler, 1999). In Study III, it was not possible to conduct a meta-analysis and summarize the findings, since the studies were designed with various methods to measure the same outcome and the results could not be compared, compiled and visualized to comment on the combined effects. An assessment of the quality of the studies was made by the authors and might have been evaluated differently by other researchers with different clinical experience and professional backgrounds.

Conducting an unstructured interview is more informal and provides prerequisites for the respondents to narrate their perception of their life situation, without the influence of the researcher (Polit & Hungler, 1999). To maintain focus on the topic but also allow the respondents to reflect freely upon their situation, the researcher needs to ask follow-up questions in order to keep the narration within the context of the topic. In Study IV, the researcher conducting the interviews disclosed her clinical experience as a district nurse to enable the respondents to feel free about speaking of matters of a more personal character. On the other hand, the interviewing researcher's professional background might have influenced some of the responses, as well as the interpretation of the women's stories. The trustworthiness was safeguarded by other researcher participating in the analysis of the data. The women who were interviewed were chosen from a strategic purposeful sample to ensure variety and diversity of age, social and economic situation, as well as time since fracture onset.

11 FINDING WAYS FORWARD

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FINDING WAYS FORWARD

This thesis includes diverse approaches related to different aspects of living with VCF and back pain. To reach a consensus on the more prominent dimension of the expressed experience, we need to further elucidate not only the similarities but also the discrepancies between the findings. VCF may have several subsequent consequences, depending on the severity and location of the fractures, even though some VCF are without symptoms. However, the more salient consequence is the constant or activity-induced intense back pain. The findings therefore indicates that targeting the women's experience of pain may be one possible way forward, which will also increase the women's ability for physical activity (Kendler et al., 2016; Riccio, Tirelli, Gimigliano, Iolascon & Gimigliano, 2013).

Traditionally, health-care providers have unquestionably decided on the best course of action for the patient in terms of care and rehabilitation from an expert point of view (Nicolaus, Specht-Leible, Bach, Oster & Schlierf, 1999). The patient is often reduced to a medical diagnosis or disease, with a dependent position in relation to the health-care provider. Research has shown that receiving information and feeling security in care pathways through the establishment of a trusting relationship is essential for a comfortable experience of receiving health-care (Östman, Ung & Falk, 2015). This implies and is conditioned by a shift from the perspective of patient to person, where the patient is one constructed role and a person is a unique being with several parallel roles (Ekman et al., 2014). A person is a human being with a personal identity and several parallel social roles consisting of norms, values and behaviors. The role of the patient is guided by the norms and rules of the health-care system itself, as well as the societal view of how a patient should act and react (Rowland & Kuper, 2017).

Östman et al. (2015) described the core concept of a person-centered agenda, as opposed to a patient-centered agenda, in the care of persons with long-term conditions.

By supporting the sense of a human being as an important part of the care, the person will increase his/her confidence and ability to handle in threatening situations in life as well as strengthen their capability for self-management (Östman et al., 2015). The concept of person-centeredness involves meeting a person as a holistic biological, social, psychological and spiritual entity with a past, present and future (Morgan & Yoder, 2012; McCormack, 2003). Within a health-care context, this implies care involving a personalized approach that takes its departure in the person's abilities, goals, views, obstacles, desires, fears and perceptions of his/her capacity, i.e. person-centered care (Ekman et al., 2011b; Fors, Taft, Ulin & Ekman, 2015; Olsson et al., 2006). By establishing a therapeutic alliance, based on a person-provider interaction characterized by sincere and supportive collaboration and communication, improvements in health-care outcomes are both possible and probable (Markris et al., 2014c; Markris et al., 2016; Ferreira et al., 2013). Including the person as a competent and capable partner in his/her care demonstrates an appreciation of the unique life situation and history of the person, recognizing his or her perspectives in the planning of individualized care and rehabilitation (Edvardsson & Nay, 2009). It can also make the person aware of what to expect, what he/she can achieve, and how to formulate realistic goals for his/her health/illness trajectory. Autonomy and self-confidence are significantly important factors when a person is vulnerable. By encouraging self-confidence, the person's participation in decision-making can be strengthened in his/her self-management abilities (Hagsten, Svensson & Gardulf, 2006; Nikolaus et al., 1999; Ekman et al., 2011a, 2011b; Östman et al., 2015; Fors et al., 2015; Olsson et al., 2006).

Therefore, a person-centered care and rehabilitation for older women with osteoporosis and VCF could lead to a sense of being taken seriously and recognized as a significant person, despite the fact that little or nothing can be done about the fracture itself. In agreement with our findings, women have described experiences of being belittled and neglected by health-care providers but desiring constructive and respectful information with regard to their fracture and wanting their illness experience to be taken seriously (Hallberg et al., 2009; Hallberg et al., 2010). If health-care providers could fulfill and reinforce these women's needs through a person-centered approach, it would strengthen their self-esteem so that they believe in their own ability and thereby reduce the feeling of isolation and induce a sense of independence leading to greater HRQoL and well-being (Suzuki et al., 2008; Suzuki et al., 2009). Older women with VCF and a substantial symptom burden in terms of back pain and physical disabilities need support to achieve an end-point in their health/ illness transition to experience stability in their life situation. They need to be perceived as trustworthy individuals and to feel confidence in health-care providers by receiving appropriate information and care based on individual resources, needs and capabilities. Meleis & Im (2002) suggest that by viewing women´s health from a perspective of transition, health-care providers might be able to percive what they have reason to value and to create continuity as a part of the experience (Meleis & Im, 2002).

FUTURE PERSPECTIVE

In an attempt to establish a person-centered approach with women living with VCF and back pain, an intervention study was initiated in 2012. The aim was to improve HRQoL, diminish the sense of disconnection and increase these women's belief in their own ability and capability for self-care and rehabilitation. The intervention was designed as a randomized, controlled trial and lasted for 12 months, comprising four visits to an osteoporosis ward and four home visits by a district nurse. A health-care plan was formulated with intermediate goals and overall goals for physical and leisure activities and physical activity on prescription was issued. Motivating interviewing was used to identify negative routines and to develop the motivation to reduce isolation and create change. A physiotherapist made home visits and an individualized exercise plan was followed up several times during the study period. A collaboration with the Röhsska Museum in Gothenburg was established with the opportunity for group sessions with the participants to break their isolation.

It became apparent early in the process that we faced major difficulties enrolling participants for the study due to the severity of back pain and co-morbidities. All the women who were contacted agreed that this was an important project; however, many of them were unable to participate due to intense back pain and physical disability due to the fracture. After two years, the study was discontinued because of problems enrolling participants. Our efforts had resulted in six women in the intervention group and six women in the control group. However, the preliminary analysis revealed significant differences between the women completing the intervention and the control group, with increased HRQoL, reduced pain and improved physical function in the intervention group. For future trials, a note of caution could be raised about the design of a study with regard to both respondent burden and difficulty enrolling a population with a high symptom burden without the risk of selection bias. This has previously been shown to be a prominent issue when addressing a vulnerable population (Mody et al., 2008; McMurdo et al., 2011).

Based on the experience acquired from the above described attempt to implement a person-centered approach, it is extremely important to design an intervention with systematically specified support based on the women's individual needs within the primary health-care context. This could emanate from a longitudinal study of women with VCF and long-term back pain in order to find facilitating and inhibiting determinants for a healthy transition but also to provide knowledge of the kind of support that would be most appropriate in order to enhance the women's HRQoL and physical ability. There is also a need for future research with the aim of identifying women with VCF and long-term back pain that are at risk of reduced HRQoL by investigating, among other things, motivation, resilience and self-esteem as well as self-efficacy.

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